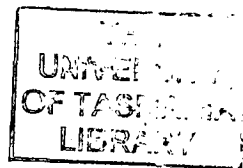


# **The consequences of ontological insecurity for caregivers of people with epilepsy**

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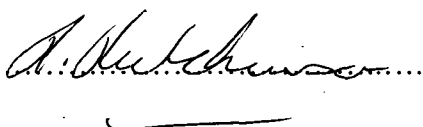
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## **ABSTRACT**

Among the world's most serious neurological conditions, epilepsy is the most common. Although its prevalence is not known with accuracy, it is estimated at between 0.5% and 2% of any population. Despite this there are few sociological studies of epilepsy and even fewer sociological studies of caregivers of people with epilepsy.

In existing studies the caregiver is assumed to share the same understandings of the condition or illness as the sick person. Further, researchers report that caregivers experience emotional stress as part of the burden of caring. This is similar to results from studies of other chronic illness and caregiving, and is usually associated with the significant physical work associated with caring for a sick person, as well as the demands upon time and the lack of support services for caregivers. Participants in this study were interviewed in order to understand the meaning of epilepsy for caregivers of people with epilepsy, to determine whether the meaning was the same for caregiver and cared-for, and whether the stress of caregiving was entirely physical.

This thesis demonstrates that caregivers have a different understanding of epilepsy from the person with epilepsy. The experience of caring for a person with epilepsy threatens ontological security. In their attempts to reinstate order, caregivers use strategies to impose predictability but find their normative expectations of the supporting social world are no longer valid. When such social expectations are breached, caregivers experience fear, uncertainty and anger. The clear connection of emotion and social structure means that policy makers can act to reduce such negative emotions by modifying the social structuring of the illness and caregiving experience.

## **DEDICATION**

This thesis is written in memory of Rick, who battled with the physical, emotional and social impact of epilepsy for five years.

## **ACKNOWLEDGMENTS**

Thank you:

To the caregivers who were so generous with their valuable time and so supportive of the project. I hope that the result is a true reflection of your dedication and valour.

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## **TABLE OF CONTENTS**

Statement of Original Authorship .....	2
Abstract.....	3
Dedication .....	4
Acknowledgements .....	5
Table of Contents .....	6
List of Tables and Appendices .....	7
Chapter One: Introduction.....	8
Chapter Two: Epilepsy .....	15
Chapter Three: Understanding the Caregiver .....	20
Chapter Four: Methodology and Research Methods .....	43
Chapter Five: Ontological Insecurity .....	50
Chapter Six: Re-Establishing Normality .....	59
Chapter Seven: The Construction of Marginalisation.....	75
Chapter Eight: Responses to Marginalisation.....	86
Chapter Nine: Discussion and Future Directions .....	100
Appendices .....	117
References .....	125

## **LIST OF TABLES**

Table 1	Medical Definitions of Seizures.....	18
Table 2...	Survey Response Data.....	45
Table 3...	Interviewee Data.....	49

## **APPENDICES**

Appendix A	Caregiver details .....	117
Appendix B	Topics for discussion .....	120
Appendix C	Information sheets and consent form .....	121
Appendix D	Survey letter and survey sheet .....	123

## **CHAPTER ONE - INTRODUCTION**

Medicine assumes that the person who has the disease is the only one who is ill. This assumption is shared by other institutions and even by family and friends, who should realise that illness is an experience that a couple has together - each differently, but one no less than the other (Frank 1995: 105).

Medical discourse privileges the position of the doctor as the primary caregiver and the dyad of doctor/patient as the only caregiving relationship of any consequence. Although most illness management is done outside the medical relationship, and the biggest problems of chronic illness are practical, social and emotional, the significance of the caregiving relationship between unpaid caregiver and the person with chronic illness has only recently received attention. The assumption that the experience of epilepsy for the caregiver was the same as for the person with epilepsy motivated this research. My project was to discover whether this is correct.

In this chapter I disclose my initial personal interest in epilepsy and caregiving. A discussion of the existing literature on epilepsy and caregivers of people with epilepsy follows, showing that the sociological literature is not only very limited, but also that a dedicated study of caregivers of people with epilepsy does not exist. The chapter concludes with an overview of the remaining sections of the thesis.

Although not a practitioner in the area of epilepsy, I have an intimate knowledge of the role of caregiver, having been in this position for five years. As a result of this experience I became involved with the Epilepsy Association of Tasmania and I am at present President of its Committee of Management. This previous and ongoing experience may have two differing effects. First, my perspective enlightens and informs the research in a sensitive and understanding manner. Second, my privileged position may also distort or misrepresent the direction of the research. I was aware of this latter problem and was prepared to monitor my questions, comments and responses accordingly.



However, the experiences of the caregivers I interviewed, although similar to mine, were also different in many ways. None of the persons who was interviewed, or who responded to the request for assistance with the research, was in my position. I had been caring for someone who was part of the full-time work-force, who was physically fit (apart from the epilepsy) and mentally alert, but emotionally very traumatised by the experience of late-onset epilepsy as it impacted on work and social situations. Caregiving for me was an experience negotiated between us. I acted as an aide and mentor, rather than a person in any way responsible for ongoing care, in a manner similar to the mothers acting as 'alert assistants' in Williams' (2000) study, although this did not prevent me *feeling* responsible when things went wrong.

The most difficult experience for me as a caregiver had been dealing with stress and it was with this in mind that I looked at research into chronic illness. Epilepsy, in my experience, was a condition quite unlike any other in its indeterminacy, uncertainty and ongoing trauma, and I anticipated that the experience of the caregiver would be influenced by the nature of the condition.

### **1.1 Previous research in epilepsy**

The literature search was very frustrating. Since the chief discourse of epilepsy is medical this is reflected in the literature. For example, a review of papers presented at the World Epilepsy Convention in 1997 displayed research on aspects of epilepsy ranging from sexual function in epilepsy, mortality, dissemination of information, support groups and alternative (non-clinical) treatments, to the use of the world-wide web. However the majority of the papers demonstrated that the principal interest for medical researchers is the search for new drugs or medical processes to control the seizures. No attention was given to caregivers.

Very little research is carried out by medical researchers on the social needs of people with epilepsy, although there are some quantitative studies on quality of life such as those of Baker *et al.* (1997) and Gilliam *et al.* (1997). Other medical research has investigated the frequency and burden of epilepsy (for example Wiebe *et al.* 1999); and the service needs for local or national populations (Taylor and Rogers 1995;

Laybourn and Hill 1994; Brown *et al.* 1998). Epilepsy has lately achieved international importance through the focus of the World Health Organisation's "Out of the Shadows" Global Campaign against Epilepsy (May 2000). This has provoked new interest and consequently more medical and social research. An example of recent research is the paper presented by de Boer (2001) on the social aspects of refractory epilepsy through life-stages. The role of the caregiver is ignored in all this research.

Other kinds of studies have been undertaken to investigate various activities centred on the person with epilepsy including: the effects of epilepsy self-help groups (Droge *et al.* 1986); epilepsy and employment (Sach 1988); the evaluation of a district epilepsy service (Taylor *et al.* 1994); mortality in epilepsy (Nashef *et al.* 1995); transition from paediatric to adult care centres (Warnell 1998); fear of seizures (Newsom-Davis *et al.* 1998); expressed emotion in the families of young people with epilepsy (Brown and Jadresic 2000); and the cost of delivering epilepsy support services in Victoria (Pollard and Deveson 2000).

The inclusion of the body as a social entity in sociological research resulted in many different studies of epilepsy with the focus on the person with epilepsy. The issue of stigma received most attention. This is apparent in the comprehensive studies of Scambler (1989), and Schneider and Conrad (1983), as well as other studies by Scambler and Hopkins (1988) and Iphofen (1990). Other aspects of epilepsy include individual responses to epilepsy (Schneider and Conrad 1981), effects on identity (Schneider 1988), and compliance behaviour (Kirchgaessler 1992).

## **1.2 Research into caregiving**

Most previous research on caregiving in epilepsy has included the caregiver's role on the periphery of an in-depth study of the person with epilepsy. Scambler and Hopkins' (1988) study, although taking into account the experiences of caregivers, still interprets caregiving through the eyes of the person with epilepsy. Scambler and Hopkins quote earlier research (West 1979) which supports the argument that the family is 'the single most important filter and point of access to lay culture, particularly when onset is early' (1988: 75). To this extent caregivers reflect the

norms of caring which are socially accepted. Scambler and Hopkins conclude that caregivers are potentially overprotective, often perceiving the person with epilepsy to be disabled. They are frequently overcome by helplessness when first confronted by seizures, and sometimes act as stigma coaches who prefer to conceal epilepsy from others rather than admit to the condition (1988: 74-79).

Schneider and Conrad's (1983) discussion of caregivers revolves around caring for children in families. Their understanding of caregivers describes two kinds of caring styles: "*open*" and "*closed*". The former caring style is described in terms of a better life outcome for the child, allowing independence and the growth of confidence, while the latter is associated with over-protection, over-anxiety, being seen to shoulder illness as a burden and, overall, contributing to a disabling influence on the child's life. Once again the approach is from the viewpoint of the person with epilepsy, and as an adjunct to the principal research, not the focus, although Schneider and Conrad do say 'their view (of the caregiver) is incomplete' (1983: 78).

There are also occasional references to the caregiver's construction of epilepsy as a limited part of research on other issues; for example, a study of the effects of stigma on family life in China (Kleinman *et al.*, 1995: 1326) and Jilek-Aall *et al.*'s (1997) study of the social effects of epilepsy in Africa. Each of these was strongly influenced by the concepts of "*felt*", "*perceived*" or "*courtesy*" stigma. Goffman's (1968) study of stigma is highly relevant to research into chronic illness. Stigma is the social reaction to the discrepancy between expected social appearance and behaviour and reality. If someone acts in a way which shows that they are aware a person with epilepsy is different because of their epilepsy, this is an example of *felt stigma* (from the viewpoint of the person with epilepsy). *Perceived stigma* describes the situation when a person with epilepsy thinks someone else may be stigmatising them while *courtesy stigma* is the transference of stigma from the person with epilepsy to a family member or friend because they are associated with the person with epilepsy.

Another example of the construction of epilepsy by the caregiver is given in Chamberlayne and King's (1997) research that studied the influence of chronic illness

on identity, drawing on the data from the *Cultures of Care* projects in Germany (1992-4) and Britain (1994-5). The project 'focussed on the role of biography in relation to chronic illness and disability' (1997: 602). Chamberlayne and King compared the experience of caring from the perspectives of two women from West Germany and two women from East Germany. One of these cared for a person with epilepsy. "*Normalisation*" is an important strategy for this caregiver enabling her to see her daughter's difficulties as 'normal and ordinary' (1997: 614). In studies of health and chronic illness normalisation is used to describe the strategies which family members use to show that the sick person is no different from any other person in many significant ways. Knafl and Deatrick (1986: 220) propose four defining criteria for normalisation: acknowledgment of impairment; the definition of family life as essentially 'normal'; social consequences of the situation as minimal; and behaviours designed to demonstrate the essential normalcy of the family to others. This may also extend to discussions of family life and routines. Chamberlayne and King argued that the results showed 'not only how individual lives are embedded in different social systems but how social structures are 'lived out' differently in individual biographies' (1997: 618).

Two recent Australian studies in social work examine the experience of caregivers of children with intractable epilepsy. This includes uncontrolled epilepsy as well as epilepsy associated with intellectual and physical problems. These are extreme examples of the burden of caregiving and the results clearly indicate this.

Murray (1993) studied parents of children with Lennox Gastaut syndrome. She identified uncertainty as a key factor in the experience and management of epilepsy. Murray identified five key dimensions of uncertainty - diagnosis, aetiology, seizure activity, treatment and prognosis and related these to the reduction of uncertainty and the importance of control. She concluded that 'the consistently high levels of uncertainty found here may indicate that causes of uncertainty external to the individuals concerned were of critical importance' (1993: 176).

Murray's study was confined to parents of children with uncontrollable epilepsy, but she did not address the experiences of caregivers with other relationships to the person with epilepsy, nor account for people who had controlled, or nearly controlled, epilepsy. McLaughlin (2001) studied a 'perceived lack of information about the needs of [families who care for a child with uncontrolled seizures] and a concern that their needs were not being met' (2001: 1). She reports that the

most difficult things for families to cope with in caring for their children were the nature of epilepsy (including the unpredictability of seizures and the stigma attached to epilepsy) and the need to give their child constant attention (2001: 1).

A statement of caregivers' needs showed that the need for information about epilepsy and the provision of respite care also ranked highly. This study, like Murray's, was also confined to caregivers whose children had uncontrollable epilepsy.

## **CONCLUSION**

In summary, although there has been much research into epilepsy, previous studies have not focussed on the whole experience of epilepsy for the caregiver, and when they have, the studies have been limited to a special population. A sociological study which was not limited by such parameters would be clearly worthwhile.

The remaining chapters in this thesis are organised as follows:

Chapter Two - Epilepsy. This chapter describes the characteristics of epilepsy, the current types of treatment and the effects of epilepsy on people with epilepsy and their caregivers. It shows that epilepsy itself is still undergoing construction as an illness.

Chapter Three - Understanding the Caregiver. This chapter reviews the literature on chronic illness and caregiving in sociological and other literature, incorporates relevant literature from the sociological study of the body, chronic illness and emotion, and relates this literature to the thesis. It shows that, until recently, understandings of caregiving have been limited to the physical and social effects, but have not analysed how emotional stress is related to social structure.

Chapter Four - Methodology and Research Methods. This chapter gives the methodological basis for the research and a detailed account of the way in which grounded theory was used. The research methods and selection of participants are described in detail.

Chapter Five - Ontological Insecurity. This chapter explains how epilepsy causes ontological insecurity in the caregiver through the experience of seizures, and the consequent disorganisation of everyday life. Time is one of the important social constructs which is changed by the experience of epilepsy.

Chapter Six - Re-establishing “normality” describes the response of the caregiver to ontological insecurity, as they seek help from the medical system, a normal response to illness. This chapter also shows that, although the dominant discourse is that of medicine, caregivers have their own specialist knowledge which is often more detailed and accurate than that of bio-medicine.

Chapter Seven - Marginalisation. In this chapter caregivers report their experiences of social exclusion as they attempt to access community resources which they expect will support them. The chapter describes the “caring contract” which caregivers assume they have entered when they take on caregiving duties.

Chapter Eight - Responses to Marginalisation. This chapter highlights the strategies of normalisation and routinisation used by caregivers for repairing breaches of social order, and the way in which frustration and failure may lead caregivers to become “activists and advocates”.

Chapter Nine - Discussion. This chapter reviews the results of this research and reflects on the policy implications of these results. The chapter concludes with the discussion of possible directions for future research.

## **CHAPTER TWO - EPILEPSY**

Epilepsy is the most common serious brain disorder in the world. As many as 100,000,000 people may have at least one seizure at some point in their lives, and an estimated 50,000,000 people have active epilepsy - this is especially common amongst children and the elderly (de Boer 2001: 36).

This chapter discusses the social and medical construction of epilepsy as a condition, highlighting the uncertainties surrounding the diagnosis, treatment and continuing care of the person with epilepsy. It shows how little is really known about a condition which is thought to affect almost 50 million people world-wide (IBE 2000: 6).

Although the prevalence of epilepsy is not known with accuracy, it is estimated to lie somewhere within the range of 0.5% (Kotsopoulos *et al.* 2001) and 2% of any population (Wiebe *et al.* 1999). Laybourn and Hill (1994) point out that a fairly simple epileptic condition has many things in common with other chronic illnesses like diabetes or asthma. They say that it

can often be controlled by medication... attacks ... are potentially concealable, vary considerably in severity, are potentially life threatening and can involve some restrictions on everyday activities (1994: 2).

They say that more severe epileptic conditions, however, with uncontrolled and frequent seizures, are similar to cerebral palsy and spina bifida, not only because they are sometimes associated with intellectual disability, but also because 'severe and frequent seizures may be extremely disabling in their own right, resulting in consistent limitations on functioning' (Laybourn and Hill 1994: 2). Epilepsy's main difference from other illnesses resides in its idiosyncratic indeterminacy of diagnosis, progress and prognosis. Unlike other chronic conditions most people with epilepsy are unaware of a seizure and have to be informed by others that it has occurred. They are aware only of the side effects of the seizure: confusion, aching, pain, incontinence and perhaps injury. In its most dramatic form a seizure also has the potential to put life at risk and appears to "possess" the body. This last characteristic has contributed greatly to the stigma attached to epilepsy.

## 2.1 What is epilepsy?

The major discourse for epilepsy is that of the medical profession. Diagnosis and treatment is given by medical practitioners and sometimes confirmed by neurologists using sophisticated technology. The medical regimen includes the prescription of drugs, and the application of legal restrictions on driving, operating equipment and work protocols. The medical discourse is centred on diagnosis, prognosis and treatment and receives its authority from the institution of medicine.

The definition of epilepsy is, as Scambler (1989: 4) suggests, 'a concept (that) belongs to a specific time and milieu ..... it is a symptom rather than a disease'. The symptom of epilepsy is the occurrence of a seizure or seizures. The working definition of epilepsy is in terms of the number of seizures which a person may have had, although even this definition is not exclusive.

Possibly up to 10% of the population will have a seizure during their lifetimes. Epilepsy, however, is concerned with recurring seizures. Most - though not all - recurring seizures earn the diagnosis of epilepsy (Pollard and Deveson, 2000).

Llewellyn's (1998) research strongly supports Scambler's contention. Having studied 100 years of medical texts she concludes that 'there is still no consensus of definition, aetiology or treatment concerning [epilepsy]' (1998: 55). Over this time definitions have varied from insanity to neurological disease, with many authorities urging medical practitioners to regard epilepsy 'as a symptom; to endeavour to find the cause; and failing this to treat the symptom' (Llewellyn 1998: 55). The medical typology of seizures varies from time to time. At present the medical definitions of types of seizures are: "*generalised*" (which includes "tonic-clonic" and "absence" seizures), and "*partial*" seizures (for more information see Table 1).

Seizures are caused by sudden, usually brief, excessive electrical discharges in a group of brain cells. Different parts of the brain can be so affected and the precise way in which epilepsy presents can vary, depending on the particular brain cells involved (IBE/ILAE/WHO 2000: 6).

These broad types are descriptive of categories of seizures (see Table 1). Some people may experience more than one. Some people may have one type and then later



another. Some may develop one type and then experience others as well. A Victorian Epilepsy Foundation leaflet (1997) states that

epilepsy has many different forms ... a blank stare, no response, tremor or jerk, a convulsion with total loss of consciousness, a strange feeling or unusual taste, lip smacking and chewing, walking around without any purpose, fiddling with clothes/objects nearby, and speaking in an unintelligible way

Some causes of epilepsy can be shown: genetic transmission; tumours; infectious diseases; acquired metabolic diseases; degenerative disorders; congenital malformations; anoxia at birth; and physical trauma (Scambler, 1989: 5-6). However, 40-70% of all sufferers may experience epilepsy with no known cause (Scambler 1989: 5).

## **2.2 Treatment of epilepsy**

Most seizures are treated with anti-epileptic drugs although, in optimal circumstances, surgery is carried out for epilepsy occurring in the left temporal lobe of the brain with some success. Just as anti-epileptic drugs are not always successful, neither is surgery. The effects of the drugs prescribed for epilepsy are not well understood, and most people with epilepsy must go through a period of adjustment to find a "therapeutic dose". For a large percentage of people with epilepsy the drugs may be ineffective or have such unpleasant side effects that some people with epilepsy cease to take them. Baker *et al.* (1997: 356) report that 44% of respondents changed medication at least once in the previous year because of unsatisfactory control and that 88% of those studied reported side effects of the drugs. Other agencies report some of the known side effects which include fatigue, dizziness, irritability, double vision, nausea, rashes, tremors and gum swelling (EFV 1997).

The prognosis for people with epilepsy is uncertain, mainly because of the uncertainty of treatment. However, Baker *et al.* say that early control is important as statistics suggest that 'the longer the epilepsy remained active, the less likely was eventual remission' (1997: 356). The inability to discover the cause for most kinds of epilepsy makes it difficult for medical practitioners to satisfactorily explain the condition to people with epilepsy, which leads to confusion, anxiety and uncertainty.

**Table 1      Medical definitions of types of seizures.**

At present the medical definitions of types of seizures, descriptive of the site and process of seizure activity in the brain are, according to Taylor (1996: 27):

**LOCALISATION-RELATED (PARTIAL EPILEPSIES AND SYNDROMES)**

Idiopathic (no known cause)

Benign focal motor epilepsy of childhood  
Benign occipital epilepsy of childhood

Symptomatic (cause known)

Simple partial epilepsies  
Complex partial epilepsies  
Cryptogenic (presumed symptomatic but aetiology unknown)

**GENERALISED EPILEPSIES**

Idiopathic

Childhood absence  
Benign myoclonic epilepsy  
Tonic-clonic awakening epilepsy  
Juvenile myoclonic epilepsy

Symptomatic

Infantile spasms (West's syndrome)  
Lennox-Gastaut syndrome  
Early myoclonic epilepsies

**UNCLASSIFIED EPILEPSIES AND SYNDROMES**

Neonatal seizures  
Undetermined epilepsies

**SPECIFIC EPILEPTIC SYNDROMES**

Situation-related seizures  
Febrile convulsions  
Acute symptomatic seizures, e.g. metabolic, drugs, alcohol  
Reflex epilepsy

This is further complicated by the fact that many other illnesses have seizures as a symptom and misdiagnosis may occur. Premature death may also occur, either associated with the risks of seizures such as drowning or accident, as a result of the seizure alone, or depression (Taylor 1996: 133). Coroners' reports do not always list epilepsy as the reason for death, noting instead, an event such as drowning.

Epilepsy may have emotional as well as physical consequences for the person with epilepsy. Lack of control, isolation and loss of confidence are some of the causes of emotional stress. There are also social consequences. De Boer (2001) reports on the influence of stigma, overprotection, legal restrictions and prejudice on the well-being and quality of life of people with epilepsy. These consequences are not unique to the person with epilepsy but are felt also by their caregivers and families. She says:

Epilepsy has a major impact on people living with the disorder - not only the affected individual, but also their family and friends.....The social consequences are frequently related to the severity of the condition, but they also stem from the concept of epilepsy that is held by the general public (de Boer 2001: 36).

## **CONCLUSION**

Epilepsy is a poorly understood condition, even from the viewpoint of medicine. Medical discourse points to a reliance on the recognition of seizure types which is often made difficult because other conditions are accompanied by seizures not classified as epileptiform. Treatment is medication-based and subject to many uncertainties related to type of medication, effective dose and individual efficacy. Prognosis is also uncertain as many people continue to have seizures despite the best efforts of health professionals. The social and emotional aspects of epilepsy are addressed only in clinical ways in medical literature (see for example, Baker *et al.* 1997; Cape and McCulloch 1999; Britten 2001), and remain focussed on the person living with the condition or paid careworkers such as described by Daykin and Clarke (2000). Thus, in order to access these aspects of the experience of epilepsy from the perspective of the caregiver, it is necessary to refer to sociological and other literature. This will be the focus of the next chapter.

### **CHAPTER THREE - UNDERSTANDING THE CAREGIVER**

...at first it was ...just terrifying and horrifying and...it was the most terrible thing we've ever been through and [now] I would say...it's more a hope thing. We hope for what he will be ...But it's been trying, and it's been really sad sometimes...and really funny at other times... Sandra/P

This research investigates the understandings of epilepsy constructed by non-professional caregivers of people with the condition. Unpaid caregivers, unlike careworkers (professional caregivers), already have a long emotional history in a relationship as spouses or parents and in this respect alone are likely to have a different response to illness.

In this chapter the historical development of the sociology of the body and current understandings of the experiences of people with chronic illnesses, and of their caregivers, is addressed. Sociological studies of caregivers and chronic illness are reviewed. The chapter also traces the connections between emotion and caregiving, and how studies of caregiving fit with recent sociological theories of emotion.

The study of epilepsy for sociologists is part of the study of chronic illness and also part of the study of the body. The relevance of the body for sociological studies is a matter of ongoing debate (Turner 1984; Bury 1991; Williams 1999), but this has not prevented investigations into the nature and experience of chronic illness (Blaxter 1976; Corbin and Strauss 1988; Thorne 1993). Caregivers became part of these studies as it was noted how their actions impinged on the person with chronic illness. Almost incidentally, it was noted that caregivers were intimately involved in the illness experience (Corbin and Strauss 1988; Doyal 1995) and, as a result, suffered from stress (Cant 1994; Taylor *et al.* 1994; Howe *et al.* 1997; Charmaz and Paterniti 1999). At the same time Hochschild's research (1975; 1979; 1983; 1989) in the developing field of the sociology of emotions drew attention to the management of emotion in both personal and working lives. These two fields were drawn together in studies of careworkers, such as nurses, who manage their emotions in an illness situation (Small 1999), or in institutions (Meerabeau and Page 1998; Bolton 2001).

### 3.1 The Sociology of the Body

An understanding of the way that social practices influence the bodily experiences of individuals was not possible until a link could be established which joined macro and micro theories of society. The penultimate step was to show theoretically how this was possible. This section gives a brief overview of the arguments that had to be overcome in order to establish that the body was a proper ground for sociological investigation.

According to Turner (1984), that a sociology of the body did not exist represents a theoretical gap in sociology. Historically, sociology began as 'a discipline which took the meaning of human interaction' (1984: 31) as the object of its inquiry and therefore was separated from eugenics, biology and physiology. Turner says (1984) that the basic premise of sociology was that knowledge of the natural world was 'socially constituted and transformed by human activity'. The phenomenon of nature was always mediated by culture. However, the body was less important than the collective reality of the social world and thus excluded from the study of society.

Turner (1984) argues, therefore, that the basic dichotomy for sociology is between self and society. He says (1984: 33) that symbolic interactionists believe that the self rests on the continuity of others' perception of continuity and that bodies of individuals are largely inconsequential. Micro-sociology, in other words, excludes the body because the 'self as social actor is socially constituted in action'. Macro-sociology, on the other hand, argues that the constituents of society are collectivities and structures, and claims structure 'cannot be reduced to the relationship between individuals' (Turner 1984: 33). A focus on bodies was not necessary, says Turner, because it was assumed that individuals have a body.

Sociological discourse in chronic illness has focussed on agency and structure, and has avoided the problem of the embodiment of chronic illness. However, Kelly and Field argue that when 'bodily demands conflict with desired presentation, the individual becomes aware of the divergence between body and self' (1996: 245). For example, in

the case of pain, 'the meanings of pain are given precedence over its physical restrictions and discomforts' (Kelly and Field, 1996: 243), despite the overwhelming influence of the physical upon the experience of the sufferers.

The postmodernist response to these studies is to deny any interpretation of body experience in terms of social reality apart from discourse. For example Foucault (1975) argues that the processes of society so tightly constrain the body that human agency is not possible, a position that Turner (1984: 250) calls "discourse determinism". According to Williams (1999: 802) postmodernists argue that lived experience is 'the fabrication of a BwO (body without organs)'. In their view bodily sensations have no meaning except constructed meaning, and therefore 'the self is the pain'. On the other hand disability theorists present a view in which disability itself is seen as 'social oppression' (Williams 1999: 803). Disability becomes simply a social construction that endorses a medicalised approach to lived experience. Structural barriers exist which exclude deviant bodies.

Both the challenges of the post-modern and the disability theorists invite the retention of a dualist approach to the body; the former by denying the link between the biological and the social, and the latter by excluding the body experience from the sociological focus. In the view of Williams, this latter position concedes the construction of the body to medicine. Both views, he says, 'write the body out' (1999: 804) in different ways.

Turner concludes that a sociology of the body 'involves the historical analysis of the spatial organisation of bodies and desire in relation to society and reason' (1984: 38). He says that a sociology of the body would need to establish four things. The first would establish the body as a part of nature and a 'medium of the self'. Secondly, it would also be necessary to make a distinction between 'the body of populations and the body of individuals' (1984: 39). A sociology of the body would recognise the body as being at the centre of political struggles, for example the social categories of age such as 'youth' are in turn connected with biological age. Finally, a sociology of the body would also have to distinguish between 'the deviance of body surfaces,

which are subject to cultural surveillance, and those deviances of the inner body (disease and illness) which are likewise objects of moral evaluation' (Turner 1984: 41). Epilepsy provides an excellent example of Turner's concerns. As a result of diagnosis, social consequences are immediately apparent. Before the condition is disclosed to others the person diagnosed with epilepsy may perceive stigmatisation which causes him/her to be anxious or afraid. Upon disclosure there may be instances of felt stigmatisation that cause social reactions of distaste, fear or discrimination. During seizures the person loses control of the body, sometimes to the extent that others take over and deliver the person to the medical system. The person with epilepsy is an example of someone with a body socially labelled defective and constrained by society into the category of the disabled. As Turner says later (1995: 17): 'The concept of the isolated, separate human organism is itself a cultural product, since the body cannot be regarded simply and exclusively as an entity inside nature.'

### **3.2 Chronic Illness**

This section examines the development of studies of chronic illness from early beginnings. Most of these were constrained by a focus on the medical aspects of illness and the limitations of accepted methodologies. Later studies benefited both from theoretical debates about the parameters of sociological investigations and concurrent research in other disciplines.

The discourse of chronic illness began as a predominantly medical one. Early sociological accounts of illness were influenced by Parsons' theory of the sick role (see Gerhardt 1989) where the medical discourse of prevention, diagnosis, treatment and care was taken for granted (Mischler 1981: 1). According to this discourse the bodies of those who were ill are the proper domain of doctors, nurses and hospitals. Within this domain bodies are constrained and ordered to the requirements of the medical system, regimented in a Foucauldian sense of discipline in a 'network of relations' (Foucault 1975: 146). When early sociological studies of chronic illness began, these were located in a medical context. Representational studies included those of Roth (1963) on tuberculosis, Blaxter (1976) on patients released from hospital, Speedling

(1982) on heart attack, Zola (1982) on physical disability, Brooks and Matson (1987) on multiple sclerosis, and Corbin and Strauss (1988) on a range of chronic illnesses. Typically describing the experience of illness in the language of medicine, the studies focussed on caregiving only as it impacts on the person with chronic illness. Studies were concerned with concepts such as illness management, illness career, rehabilitation, 'needs' of the patient, and coping lifestyles. Later studies of the person with a chronic illness could be seen 'as an attempt to move away from the rehabilitation models' toward research which either examined 'the consequences of illness' or 'the significance of illness in the wider context of culture and society' (Williams and Busby 2000: 172).

Julius Roth's (1963) research indicates that people with an illness operate as though there are a series of stages of recovery towards an endpoint or goal, which he calls an "illness career". The sequence and timing of intermediate stages towards this goal he calls an "illness timetable". Intermediate stages may be, in turn, divided into even smaller segments by "markers" which act as signposts towards eventual recovery. Roth says (1963: 99)

In all timetables we find dividing points for events that serve as signposts for progress in a given direction...In retrospect, such signposts may also serve as reference points from which one may predict and measure further progress...As the reference points become less rigid and less clear-cut, they must be discovered and interpreted through observation and through interaction with others...The more unclear the reference points are, the harder it is for members of a career group to know where they stand in relation to others.

Blaxter's early and very comprehensive study of people discharged from hospital, specifically looks at problems related to family and social relationships. Stigma is prominent among these, but she also reports the 'strain which impairment can put upon marital relationships' (1976: 204) and the friction which can develop. Blaxter comments on marriages that break up because of chronic illness and consequently cause work for social workers that may have been avoided with appropriate intervention at an earlier stage (1976: 206). This is also confirmed by Speedling's (1982) research. Blaxter notes, and Speedling's study confirms, that men, used to a



full working life, feel particularly isolated by illness, and that the major problem is that there is 'no money for either social activities outside the home or the materials for hobbies within it' (1976: 208). Blaxter identifies the reasons for isolation as partly those above, but believes that isolation is also influenced by the amount and type of disability, for example, if social communication is made difficult through deafness.

Blaxter also argues that generally there is a strong correlation between 'the existence of social and other problems and a poor relationship with the medical profession in general and the general practitioner in particular' (1976: 211). She notes that the social needs of ill people are based on the belief that the local community ought to be involved in caring for its disabled members. She finds that provisions for dealing with isolation, providing employment and generally supporting families are 'wholly inadequate' (1976: 213). This early study highlighted many issues that were supported by later researchers. For example, in a study of multiple sclerosis, Brooks and Matson (1987) similarly identify the economic cost of caring, the importance of family support, the experience of stigma, the importance of work in defining identity and the individual's need for independence.

In addition, Speedling (1982) also identifies the need for better communication between doctors and patients and better information about what is expected to happen concerning care in the home. Brooks and Matson (1987) point out that doctor-patient relationships, social relationships and self perceptions are all affected by chronic illness. They draw attention to the fact that almost all the work that is undertaken with chronic illness occurs outside medical facilities (Brooks and Matson 1987: 77).

Lack of information is a recurring theme in research into chronic illness. Korsch and Negrete's (1968) studied GP consultations, where, even where a clear diagnosis was possible, 50% of mothers were found to be unaware of the cause of illness, and 20% of mothers received no statement at all about what was wrong with their child.

Studies show that one of the principal concerns for patients is that information either does not appear to be available or they suspect that it is being withheld (Freund and

McGuire 1995). Ariss (1997) reports that people with HIV/AIDS experience similar problems, leading to the formation of the Treatment Information Project which translated medical information into a format designed to inform, and to be read by, patients.

More recent studies of chronic illness fall into two categories (Williams and Busby 2000: 172). Researchers in the first category comment on topics such as 'employment, sexuality, environmental barriers and so on' (which are already in the sociological domain), or constructions of illness or disability. Studies such as those of Wiener 1975 (uncertainty), Radley and Green 1985 (styles of adjustment), Thorne 1993 (doctor-patient relationships), Charmaz 1994 (identity dilemmas), Little *et al.* 2000 (vulnerability), Ezzy 2000 (time) are examples of concept related topics. Constructions of illness or disability include those of Mischler 1981 (social construction of illness), Waxler 1981 (social construction of leprosy), Kitwood 1993 (social construction of senile dementia), Posner 1998 (herpes simplex), and Millen 2001 (chronic fatigue syndrome).

The social relationship between doctors and families is established and reinforced through discourse and experience of acute illness. As Thorne (1993) says, the expectation at the beginning is that the health professional will understand the problem and find a solution that is in the best interests of the patient and family. Caregivers and patients expect that their experience will follow the usual medical path of diagnosis, treatment and cure. However they soon begin to understand that chronic illness is not the same as acute illness.

Charmaz's (1991, 1994) significant contributions also focus on the experiences of people with chronic illness. Charmaz reports on a very broad range of people with chronic illness in terms of 'the private face of a public problem' (1991: 4). She considers that the experience of chronic illness parallels other life crises such as job loss, divorce or abuse (1991: 5-6). Her examples illustrate the way in which people experience illness, how they live with it and the meaning of illness in a temporal sense. Charmaz's (1994) discussion of chronic illness relates loss of identity to the illness experiences of men. She argues that chronic illness 'threatens men's taken-for-granted

masculine identities and leads to identity dilemmas that can re-occur again and again' (1994: 269).

Temporality is an important concept for studies of chronic illness. Melucci's discussion of "social time" and "inner time" asserts that "social time", that is, time regulated by social rhythms and roles, and "inner time", the way that we live 'in our inner experiences, affections and emotions' represents a tension which produces a loss of *telos*, 'in which the present becomes the inestimable measure of the sense of things' (1998: 182). The component elements of inner time are that time is *cyclical*, *simultaneous*, *multidirectional*, *immeasurable* and *unpredictable*. 'Inner time [is] multiple and discontinuous' where different times overlap, succeed and intersect with one another (Melucci 1998: 183). Reading accounts of chronic illness experiences, these terms resonate with meaning as people relate the way they cope with a disability which makes social time problematic.

In contrast with the first category where the emphasis was on concepts and constructions relating to chronic illness, the second category relates to writers who attempt to understand the meanings of illness experience "ontologically" (Williams and Busby 2000: 172). The research of, for example, Frank (1995) on cancer, Karp (1996) on depression; and Crouch and McKenzie (2000) on recovery from cancer, falls into this section.

Crouch and McKenzie's (2000) study of women recovering from breast cancer highlights the uncertainty surrounding chronic illnesses. Drawing on the concept of "ontological security" (Giddens 1991), they argue that the experience of chronic illness places people in a position where ordinary life no longer has filters to allow sick people to ignore uncertainty. In these women 'an episode of the disease endures in consciousness as ineluctable uncertainty for the persons in particular'. The cancer is regarded as an ever-present threat to life, even when it is not active. Citing Giddens (1990), they say that people in society live with a 'processual bracketing of ontological insecurity at a non-conscious level. [This] allows individuals to take for granted continuity and identity' (Crouch and MacKenzie 2000: 3).

Giddens asserts that 'ontological security' is closely associated with understandings of what is 'practical consciousness' (1991: 36). In our daily lives he argues, we discount the existence of chaos by establishing routines and practices to create order. All social life is based on these taken for granted understandings which we trust will be upheld through daily experience. These social practices 'are constitutive of an emotional acceptance of the reality of the external world without which a secure human existence is impossible' (Giddens 1991: 42). Questions which confront people include 'existence itself', 'relations between the external world and human life', the 'existence of other persons' and the 'continuity of self identity' (Giddens 1991: 47-52).

Studies of chronic illness have exhibited a growing awareness of the limitations of early research; moving from the strictly medicalised gaze of early research into chronic illness and management orientations, to phenomenological studies and experiential reporting of illness. Reporting on caregivers emerged as an adjunct to the experience of the person with chronic illness before becoming an area of interest in its own right. Principal themes and issues from these studies range from discussions of medical management such as illness career, doctor-patient relationships, diagnosis and compliance to a focus on social issues such as stigma, family and social support, the need for information, loss of identity, temporality and ontological security.

### **3.3 Sociological studies of caregiving**

This section reviews studies of caregiving and shows how this has evolved from being part of the study of a sick person to research that focusses on aspects of caregiving, or careworking, or the total experience. Since emotion emerges as an important part of the expressed accounts of caregivers, different theories of emotion are discussed to determine whether the experiences of caregivers may be analysed in terms of these theoretical frameworks. Studies of caregiving that incorporate the management of emotion or identify different emotions experienced by caregivers are also reviewed.

The plea for understanding the caregiver's burden has been put eloquently by many researchers on behalf of caregivers (see, for example, Schneider 1988: 35, Corbin and Strauss 1988: 316, Scambler and Hopkins 1988: 174, Anderson and Bury 1988: 8, and

Laybourn and Hill 1994: 4). Initially, chapters on aspects of the caregiver's experience were found in books on specific chronic illness experience such as those of Blaxter (1976), Zola (1982), Speedling (1982) and Corbin and Strauss (1988). In early studies such as those of Blaxter (1976) and Brooks and Matson (1987) the caregiver, although present, was nonetheless of minor interest to the researcher compared with the person who had the illness. Where aspects of caregiving attracted interest, these were often related to concepts such as stigma, which is a continuing subject of sociological interest. Even in later studies such as those of Charmaz (1991; 1994) caregivers are only briefly mentioned in their supportive role, for example, for their importance in 'affirming men's personal identity and worth.....derived from their central positions as husbands' (Charmaz 1994: 273).

Corbin and Strauss take as their focus the complementary roles of caregiver and the person with chronic illness. In their words, the major focus is 'on effectively managing chronic illness at home and the relationship of the psychological experiences of couples to the success of that undertaking' (1988: xi). First conceived as a study of the partners of the chronically ill, the focus of the research was changed to include the person with chronic illness as well. They say (1988: 12) 'it became very clear after the first interview that to understand the impact of illness on one partner of a dyadic relationship it is necessary to grasp its meaning for the other partner.'

This is similar to most early studies of chronic illness in which the meaning of the illness experience is always focussed on the person with chronic illness. In such studies the personal perspective of the caregiver, and the caregiver's own feelings, needs and motivations is always seen from the perspective of the person with chronic illness. The theme of illness management is prominent and this, together with the limitation of the study to the home environment, excludes a great deal of social life, activities and interaction in which the caregiver may be involved. Although such studies show much of the experience of illness, they omit the unique perspective of the caregiver.

In his (1996) study of depression, Karp acknowledges the role of the caregiver by recounting the experiences of four caregivers of people with depressive conditions. He hypothesises that family and friends 'move through a predictable socialisation process' (1996: 163). This process moves from 'bewilderment and consternation' to a desire for information about depression, to a 'sometimes lengthy period of heroic efforts to save or cure the depressed person'. If this is found to fail, in order to protect their own health, the caregiver begins 'the process of retreating from the sick person' (Karp 1996: 163). Karp comments that the stories of caregiving show how 'depressive illness poses distinctive involvement dilemmas for the family and friends of an afflicted person' (1996: 162).

Larger studies include the family in the overall account of chronic illness, but few take caregiving as an exclusive concern, although the stresses of caregiving are frequently reported. Led to some extent by feminist writers, there is a broad body of work that comments on the practical implications of stress for the caregiver and their need for social support (see Strauss and Glaser 1975; Corbin and Strauss 1988; Glazer 1988; Taylor *et al.* 1995; Charmaz and Paterniti 1999). The latter argue (1999: 146) that 'women do the bulk of informal caregiving, providing everyday care to ailing family members, and, sometimes, intensive long-term care for those who are chronically and terminally ill'. This is a view often acknowledged by others, including, for example, Brooks and Matson (1987).

James (1998) notes that the number of unwaged carers in the UK in 1990 was 'more than the whole National Health System workforce' (1998: 218). The ABS (1998: 1) found that in Australia, in 1998, there were '2.3 million people who provided some assistance to those who needed help because of disability or ageing'. However, it is difficult to reach an agreed-upon estimate of the number of caregivers, and certainly more difficult to do so cross culturally due to differing definitions and forms of measurement.

Strauss and Corbin comment that 'home care is an undernourished child of the American health care system, focussed as it [is] on acute care and hospital regimes' (quoted in Charmaz and Paterniti 1999: 594). According to Glazer (1988: 363), hospitals in the US and other western countries where the public health care system is not strong, transfer health work to families in order to maximise efficiency and profits. The US health system, she believes, is not based on individual responsibility for health care, but on family support, a process she calls "de-hospitalisation" (Glazer 1988: 365). In 1985, the savings of this process for US hospitals were estimated to be \$US10 billion. Glazer (1988: 366) argues that, as well as home care being seen as an extension of women's caring work, it is increasingly becoming a hi-tech extension of hospital work. Caregivers work to hospital timetables, give drugs, administer physiotherapy programmes and monitor sick persons constantly in order to report on their progress to doctors. Sick persons, she says, are sent home earlier than before and caregivers are given only minimal training for their care.

Glazer (1988: 368) argues that unskilled family members or minimally skilled careworkers are performing care usually undertaken by highly skilled, highly regulated and highly paid careworkers. In this way the old ideas of a division between home and 'the core of social life (the economy, politics, education and so on)' are unsupported (Glazer 1988: 370), when the links between them are shown to be as clear as they are in the case of the "work transfer" (1988: 362) of health care. In summary, in addition to normative expectations that woman's "natural role" is to be a caregiver, women are also being appropriated as care labour by the health system.

Evidence exists that labour market inflexibility marginalises caregivers and available care options and facilities disadvantage caregivers who may wish to work (Baldwin and Glendinning 1983: 70). The marginalisation of caregivers is obviously not recognised in the labour market, or in terms of their contributions to the economy of western societies.

Myers and MacDonald (1996) report on the policies that stress the involvement of the caregiver in the process of assessment and care management programmes. They

further identify areas of potential conflict in interaction between health professionals, carer and user in the arrangements to be made (1996: 89). Olsen *et al.* (1997) address the problem of the involvement of caregivers in service planning. Carers are considered to be 'caught in the middle' between the possibility of influencing policy through collective representation or intervening directly at the care interface with the health professional. Neither of these options is considered to be likely for most caregivers (1997: 120-121). They identify a gap between 'policy making and policy implementation' and suggest that aspects of policy implementations such as budget restrictions represent tensions when opposed to a 'needs led' policy (Olsen *et al.* 1997: 122). Caregivers are recognised as disempowered, on the basis of their inability to act for themselves because of their caregiving responsibilities and also in terms of being unable to determine change.

Empirical research into caregiving also approximates the typology of chronic illness suggested by Williams and Busby (2000). Studies with a medical orientation occurred earlier and include quantitative studies that measure aspects of caregiving such as adjustment to chronic illness (Klein *et al.* 1967) or "psychophysiologic" distress (Foxall *et al.* 1986). Studies related to the cultural or social significance of illness, or concepts that are already in use, encompass studies such as: Fengler and Goodrich (1979) on role overload and isolation, Knafl and Deatrick (1986) on normalisation, Orona (1990) on temporality and identity loss, Garey (1998) on 'doing motherhood', and Williams (2000) on gendered caregiving. Finally, caregiving studies that attempt to understand the meanings of illness experience 'ontologically', would include those of Karp (2001), Poindexter (2001) and Grbich *et al.* (2001).

In a most comprehensive study David Karp (2001) examined the lives of sixty caregivers of people with mental illness in the USA. His study of caregivers shows the importance of cultural values in directing caregiver's actions. Although he acknowledges that mental illness 'physically and emotionally exhausts family caregivers' he also relates their acceptance of the role of caregiver to pervasive cultural values and the social structure which limits the responsibility of society to intervention only when there is no other choice. He argues that Americans 'are deeply



conflicted about what they owe themselves and what they owe others' (2001: 236). He draws attention to what he regards as the central problem of caregiving: the ambiguous messages which are part of U.S. culture, where on one hand the family is expected to care for its members almost unsupported by local, state or federal authorities and on the other individuals are expected to be responsible for themselves.

Karp develops his earlier (1996) framework of an illness '*career path*' to include caregivers. He says that the concept of 'career path' is based on earlier work by Glaser and Strauss on illness trajectories (Karp 2001: 73). He argues not only that there are 'predictable changes in responsibility over time' but there are corresponding 'comparable and patterned transformations in caregivers' emotions'. The initial period after diagnosis he terms '*emotional anomie*'; which 'reflects the sheer bewilderment of a life that has moved rapidly from coherence and predictability to chaos and disorder' (Karp 2001: 27). He also addresses the concept of obligation, arguing that 'feelings of obligation are tied to one's social location within the family' (2001: 29), although later referring to the way in which the disintegration of social bonds may have diminished felt obligations towards others .

Studies of caregiving indicate themes and concepts already identified in studies of chronic illness such as normalisation, temporality, identity dilemmas, gender, illness trajectories, career paths and social isolation. Karp's (2001) study while acknowledging the work load of caregiving also introduces the idea of emotions changing over time and the importance of social obligation, both within the family and within society.

Emotion is clearly present in earlier work in caregiving but it remains unanalysed and untheorised, for example in Corbin and Strauss' (1988) study of the joint management of chronic illness by the people with chronic illness and their spouses. In this research caregivers clearly express emotional burden although the researchers do not specifically address this facet of the caregivers' experience. Emotion work, and the influence of social values, is apparent in almost every quoted piece of narrative, as this excerpt (1988: 305) demonstrates:

I felt that I wasn't getting enough attention and I didn't want to do anything for anybody because nobody was doing anything for me. I felt sorry for myself. At the same time I didn't like that feeling because I felt it was very selfish. I felt very guilty about it, which compounded the self-pity. It was like a vicious circle.

Although so obvious in the commentary of the caregiver, the importance of the emotional content has been bypassed by the research focus on the three lines of management - biographical, illness related and everyday work. Charmaz (1994) similarly recorded instances of expressed emotion without including this in her analysis. For example, Charmaz reports the reaction of one male to a heart attack:

he became furious when his doctor told him that he had had a heart attack. When I asked him what raised his fury, he juxtaposed the finality of heart disease with the injustice of having paid his dues already by stopping smoking, limiting drinking, getting in shape, and losing weight (1994: 272).

Given the prominent place of emotion in these account, the lack of any analysis of it is a grave lacunae especially as theories of emotion have the potential to explain the connection of the individual to social structure. As Williams and Bendelow (1996: 46) state, human emotions are fundamentally embodied, 'an on-going structure of lived experience, and an active mode of being-in-the-world; one which provides the existential basis of culture and self, human sociability and social institutions'. In addition they suggest that 'emotion provides the "missing link" between personal troubles and broader public issues of social structure' (1996: 46-47). The relationship of emotion to the caregiving experience needs to be explored in sociological terms. The next section looks briefly at the historical debates, and current theories in the sociology of emotion to determine how emotions, social structure and caregiving are linked.

### **3.4 The Sociology of Emotion**

Widely viewed for years as a biological product of the body, or part of the subject matter of psychology, philosophy or psychoanalysis, the sociological study of emotions has been the object of serious discussion and debate for a little over twenty-five years. This is not to say that social scientists have not acknowledged that emotions had an effect, but if they did, it was as 'a residual category' (Scheff 1990:

11). The move across all academic disciplines towards research that was objective, measurable and rational, meant that a sociology of the emotions was put on hold for a considerable time. Micro-sociology and macro-sociology alike excluded the body from investigation, and consequently also excluded the emotions, as emotion is a sensation experienced similar to the way sensations of hearing, touch and smell are experienced. In fact Hochschild describes emotion 'as a sense, and our most precious one' (1990: 119). As we learn to identify sounds, smells and textures in a social way, so we also learn to identify the emotions we feel.

Williams (2001: 39) considers that extreme theoretical positions range from 'organismic' (a position where emotions are regarded as having a purely physiological basis as for example, described by Darwin 1859 and James 1922), to versions of 'constructionist' (the position that emotions are purely a social construct and have no physiological basis). The problem with these extreme positions, he says, is that the first denies the influence of socialisation and the second excludes any bodily influence. Williams agrees with Hochschild (1983) that what is missing from organismic accounts is a 'more subtle and sophisticated notion of how social and cultural factors impinge upon emotional experience and expression' (Williams 2001: 40).

Theorists in the sociology of the emotions have now abandoned a totally biological basis for emotions and have moved towards a more integrated view. Although agreeing that emotions have some biological input and some social input, many other issues are still debatable including those which address the conditions under which emotions occur, how they occur and whether emotions have an effect on other social structures and if so, how. In his overview of theories of emotion, Gordon (1985: 134) identifies three different approaches: behavioural exchange theories, conflict theories and interactionist theories.

### **3.4.1 Behavioural exchange theory**

Behavioural exchange theory is predicated on the belief that human action is defined by the relations of transactions. Homans (Gordon 1985: 137) argues that any interaction can be analysed by addressing the dimensions of power, status or reward.

Loss of status results in anger or frustration and increase in status leads to positive emotions. Although emotions are considered to be innate, the responses to situations are learned and then no further learning is necessary. Supporting this view, Barbalet (1998: 26) states that 'emotions must be understood within the structural relations of power and status which elicit them'. However Gordon (1985: 137) argues that 'a comprehensive theory of emotions should include an explanation of emotion's consequences as well as social origins' and sees several objections to exchange theory. First, it does not address emotions that arise, for example, from social injustice. Second, it lacks the temporal framework to account for emotions in enduring complex relationships. Third, the theory excludes spontaneous emotion in which self-interest appears to be irrelevant (1985: 135-136). These objections would appear to deny the usefulness of social exchange theory for the emotions expressed by caregivers.

### **3.4.2 Conflict theories**

Conflict theories proceed from the understanding that all individuals are members of competing social groups and classes. Emotions are biologically based, and produce automatic reactions to some behaviours. For Coser (Gordon 1985: 138) external hostility increases group solidarity. While anger may be directed at a person it may also be directed at the social sources of outcomes, for example, at a class situation. In this way conflict theories relate micro to macro structure.

Collins (1990) sees emotion as a means to create solidarity and loyalty. He says that individuals 'acquire or lose emotional energy in both power and status interactions. Order givers gain [it], order takers lose it...' (Collins 1990: 39). This does not only apply to small groups but also to large gatherings. However, a problem for this theory is that 'it focusses on emotions relevant to political conflict and solidarity, rather than on the full range of human emotions' (Gordon 1985: 140). Conflict theories of emotion may have some relevance in understanding caregivers, for example, in explaining emotional responses to health professionals, and other people in authority positions.

### 3.4.3 Symbolic Interactionism

Symbolic interactionist theories provide a micro-social explanation of emotions. This explanation draws upon the theories of Durkheim and Goffman and emphasises 'the uniquely human capacity for creating, manipulating and modifying symbols to direct one's own behaviour and to influence others' behaviour' (Gordon 1990: 141).

Goffman's work (1961, 1963, 1967) is extremely important to these theories as it underpins the interactionist approach by identifying the rules of social interaction.

Hochschild's illuminating view of the rules of emotion management (1979) is only one of the perspectives developed from Goffman's vision. Although accused of being limited in his observations to the presentation of self and not attuned to feelings, Goffman shows that most, if not all, of everyday life is constrained and bound by interaction rules. Hochschild believes that Goffman's special insight was to establish an intermediate level between individual and social structure where interaction at the micro level could be studied (Hochschild 1979: 556).

We are led back to appreciate the importance of Goffman's work ... as the critical set of conceptual connecting tissues by which structure and personality, real in their own right, are more precisely joined (1979: 557).

Goffman does not explore these connections, with the result that his 'actor' is 'exquisitely attuned to outward appearance, but his glances inward at subjective feeling are fleeting and blurred' (Hochschild 1979: 557). His illustrations, Hochschild says, demonstrate not just impression management but also the management of feeling, but Goffman 'fails to distinguish the first from the second' (1979: 558). What Goffman does brilliantly is to focus our attention on the moment of interaction. By doing this he has alerted us to the possibility of other dimensions of social interaction.

Hochschild's (1975) own contribution to the sociology of the emotions is to meld Darwin's organismic basis of emotion, with Freud's view that emotion provides a 'signal function' to alert the individual of danger and Goffman's analysis of the rules of interaction. This provides a necessary link between the physiology of the body and social interaction. The problem then becomes the identification of the source of the danger to which Freud alludes; the modern basis of fear. Scheff (1990) and Turner

(2000) address this issue. Scheff identifies the social bond as the most important basis for emotion and proposes that emotions emerge at the time of interaction between two or more people taking into account, in Goffmanian terms "reciprocal ratification" of each of the parties as "legitimate participants" (Scheff 1990: 6). The significant thing about the human social bond is that it 'must be constantly tested and renewed if it is to remain intact' (Scheff 1990: 8). In so doing, Scheff provides a reason for the importance of Freud's signal function of emotion: the necessity to protect the social bond.

He argues that human desire is to protect the social bond because this in turn protects the individual from the pain of leading an isolated existence (Scheff 1990: 10). In this respect the two predominant and important emotions are pride and shame, the emotions which individuals use to reflect on their own contribution to interaction. Scheff builds his theory on the concept of interaction rituals proposed by Goffman of whom he says 'unlike most who discuss the social encounter, [he] did not limit his analysis to thought and behaviour but included emotion as an important component' (Scheff 1990: 7). However, Scheff restricts his discussion of emotions because he looks only at introspective consequences of interaction and does not take into account other components of interaction. In so doing, he ignores the importance of normative expectations and consequently the emergence of other emotions equally important to social processes.

Turner (2000) suggests a more sophisticated basis for the genesis of emotion. He bases his hypothesis on natural selection and the need at some stage for humans to use emotions to their advantage. From this evolutionary perspective he suggests that the major emotions once performed functions that were crucial to social survival. Turner's theory of emotions draws from previous work in symbolic interactionism, dramaturgical analysis, power and status theories and expectation-states theories (Turner 1999: 133). He argues that any interaction begins with a condition in which many kinds of expectations are combined into one general kind of state. 'Emotions are aroused by the degree of congruity or incongruity between (1) what is expected and (2) what is experienced in a situation; and when there is high incongruity, emotional

arousal ensues.' He continues '...individuals carry with them into any interaction a past biography of emotional displays and habitual use of defence mechanisms; and these exert a cumulative effect on the production of emotional energy during the course of any particular interaction' (1999: 134). Like Scheff, Turner argues that 'once a social structure exists, it circumscribes the flow of emotions in encounters' (2000: 148). It does this, he says, by taking into account culture, social structural relations and interpersonal needs.

Garfinkel (1967) and his students exposed the consequences of continued stressing of social bonds in a unique set of experiments. These experiments also clearly showed how emotion emerges when the expectations that form part of the social bond are not met, although Garfinkel did not address this issue. In each case where expected ordinary social transactions took place and were breached individuals responded with bewilderment and anger. The taken-for-granted status of most of our interaction is only revealed where a response either exceeds or disconfirms our expectations.

### **3.5 Empirical studies of caregivers and emotions**

The focus on caregivers became centred in the health sciences and nursing where research on caregivers refers in the main to the impact of caring on paid staff in institutions. The concept of 'emotional labor' introduced by Hochschild (1979) found immediate support within the caring world of nursing. Few researchers examine the emergence of emotion in the domain of chronic illness except for studies in professional caregiving and they follow almost invariably Hochschild's interest in the management of emotions (see for example Treweek 1996; Meerabeau and Page 1998). This is not to suggest that emotions as a part of nursing, or patient behaviour, or visitor behaviour or even as part of physician behaviour had not been noticed. It had merely not been studied. James (1992: 504) reports

however informally and incoherently, emotional labour has long been part of public health care through the work of chaplains, the support of friends and family, the work of clerical officers, the 'subjective' relationships of health care workers and patients, and the friendliness of domestic staff.

Her study of carework at a hospice shows that caring labour is often frustrated by organisational requirements, or routines, that override the needs of the patient. James says (1992: 495)

One of the problems facing nursing staff was that tensions between organisational priorities and organising individual patient care may appear insurmountable even when staff actively seek to give 'good patient care'.

Using Hochschild's (1979) definition, nurses are performing "emotional labor" when they act on their emotions to reflect the demands of their job, not "emotion work". This definition clearly states that emotion management as part of paid employment is emotional labour. I argue that the desire to use "emotion work" to refer to emotion management in nursing and related occupations stems from the discourse which identifies females with innate caring capacities. As Small (1999: 251) says, 'as long as caring and nurturing are seen as archetypal feminine traits, then emotional labour will continue to be largely "women's responsibility"'.

Aspects of emotion management in the nursing role are the subject of Meerabeau and Page's research (1998) in the context of the revival of heart arrest patients. The suppression of anger and sadness, and the expression of laughter are identified as factors in the management of anxiety. In a different context Treweek (1996: 115) argues that 'emotion skills are harnessed by workers to allow them to get through their work and create order in the home' in her study of care assistants in a nursing home. She states that these women use 'emotion work' and not 'emotional labour' because it is not in conflict with the kind of emotion work usually done by women. Treweek says that 'verbal coercion and emotional manipulation can be as much a part of emotion work as loving, facilitating and caring' (1996: 119).

Bolton (2001) also argues that when nurses juggle emotions in response to different demands they are in fact performing emotion work. Nurses are reported to be very much aware of the way they must 'actively work on their emotions in order to present the recognisable face of the professional caregiver' (2001: 92). Even more challenging is Little *et al.*'s (2000) assertion that physicians are 'vulnerable' to the demands and



'implicit powers' of patients (2000: 499). They give as one example, an oncologist who says 'nowadays I'm finding it more important for my own survival, for the next twenty years of my practising life, *not* to carry their burden' (2000: 499). However this also seems to be the practice of 'emotional labour' as doctors are also paid for controlling their emotions in the same way as nurses or other careworkers. The interpretations of Treweek, Bolton, and Little *et al.* are highly debatable if Hochschild's definition of 'emotion labour' is followed.

These studies of emotion focus only on the management aspects identified by Hochschild. However it is apparent from caregivers' accounts that their expressed emotions are not only concerned with the management of their own emotion, or even the management of the emotions of others. Earlier studies of caregiving, such as Blaxter's (1976) comparative research into chronic illnesses and Corbin and Strauss' (1988) study along similar lines, were full of references to expressed emotion, most of this in the excerpts of interviews or the interviewer's notes. The latest examples of caregiving research and its relation to emotion show that health professionals are very much aware of the emotional component of working with ill people (Small 1999; Williams 2000). Similarly the most recent examples of caregiving research also comment on the expressed emotions and 'emotion work' of caregivers (Garey 1998; Poindexter 2001). Grbich *et al.* declare that previous research makes plain

the experience of caring for a terminal family member is emotionally stressful, that health professionals have not addressed this issue, and that, in the absence of support caregivers have discovered their own ways of coping (2001: 31).

However, with the exception of Karp (2001), most studies are confined to the descriptive aspects of these emotions without analysing the relationship of emotion to social interaction or structure.

## **CONCLUSION**

The existing literature on chronic illness draws attention to the impact of chronic illness on the principal caregiver or partner of the person with chronic illness. The literature on emotion has focussed on the management of emotion in caregivers in health related occupations. But, despite common knowledge of their research

experience, few have devoted time to in-depth communication with unwaged caregivers in order to record the whole of their experience, which, as Frank says (1995: 105), is different from the person experiencing the illness, although shared. It is not only part of the experience of the person with chronic illness, not only part of the management of the illness, not just a response to the questions of others but an important aspect of life, at that time, for that particular person.

The emotional component of caregivers' accounts has also been treated lightly, in most cases taking the expression of emotion as a corollary to caregiving without exploring the relationship of emotion to elements of social structure. Emotion has emerged as an important element in accounts of chronic illness, at first as a part of interviews with people with chronic illness or their caregivers, and in later research, as an integral part of the study. Theories of emotion offer explanations for many situations in which caregivers express emotion, for example, situations in which power and status relationships, class positions, and breached expectations, result in expressed emotion.

Insights from the literature on caregiving, chronic illness and emotion show how necessary it is to find a complementary methodology that allows the embodied experience of the caregiver to inform the research. How this was achieved is described in the next chapter.

## **CHAPTER FOUR - METHODOLOGY AND RESEARCH**

### **METHODS**

Most qualitative research assumes that, in order to understand people's behaviour, we must attempt to understand the meanings and interpretations that people give to their behaviour (Rice and Ezzy 1999: 2).

This chapter covers the choice of research methods and gives a detailed account of the way the research progressed. The advantages of grounded research for this study are described and difficulties and advantages that were experienced during the research are also discussed.

The kind of qualitative study to be undertaken depends very much on the relevance of methodology to the research method. Because this research is focussed on the areas of the body, chronic illness and the emotions, the closest philosophical approach to this particular kind of study is offered by phenomenology, in particular, the interpretation of hermeneutics by Ricoeur (1984-1986) described by Polkinghorne (1988: 131ff).

#### **4.1 Methodological approach**

Drawing on Dilthey (1900) who proposed that the same operations that resulted in the understanding of written texts could be applied to understanding the social world of meaning, in a similar way Ricoeur widened the application of hermeneutics to the meaning of social action. Ricoeur says that the 'researcher is like the reader of a text ..... human action as well as literary works can be read as texts' (quoted in Polkinghorne 1988: 134) An act is interpreted in a process like judicial reasoning. It can never be said to be true in any other sense except in a probabilistic way.

Understanding arrives through the interpretation of meanings in interaction and is negotiated on the basis of previously known social meanings; the principle of "fusing of horizons". The author of an action is not necessarily aware of his/her action and therefore interpretation must take place as well as introspection. As Cosgrove (2000: 256) says, 'the phenomenological approach is a descriptive approach aimed at identifying the essential structures of an experience.' Studies using hermeneutics as a framework require the researcher to interpret the data bearing in mind the beliefs,

practices, concepts and values of the social world. Problems associated with phenomenological research include the loss of predictive ability and the problem of validation, although these can be addressed by the rigour, quality and realism of the individual research project.

Grounded theory has the potential to combine the depth of phenomenological understanding with the insights of symbolic interactionism. This allows not only for the 'insider's point of view' (Kellehear, 1993a) but also for the identification of themes and concepts which might be useful as the basis for further research. The strength of grounded theory - continuing comparison of data and concepts as the research progresses in a hermeneutically informed way - enables the researcher to constantly modify and hone emerging aspects of theory, but at the same time ensure that the theory is directly related to the data. The data are examined initially to identify constant themes. These themes are then coded and re-coded so that concepts can be developed in a progressively more general and abstract manner. The core category is developed through this process. The relationship between the meaning and experiences of the research subjects is illuminated by the ongoing comparison of the categories and codes. My approach has been more closely allied to that of Glaser, in terms of his emphasis on the emergent process and his understanding of the open coding practice (Grbich 1997).

#### **4.2 Recruitment and sample**

The interviewees for this project were drawn from the membership of two voluntary associations with which caregivers of people with epilepsy were likely to be associated. One of the problems of such a research population is that they comprise a group of people who may be more willing to be identified with those who are disabled or 'epileptic' than others and therefore not representative of the range of caregivers. Droge *et al.* (1986: 152) surmise that people who join such associations may be representative of people with epilepsy who have "come out". This may be also be probable of caregivers of people with epilepsy. However this same effect may also help to counterbalance the usual reluctance of people to be associated with the stigma

of research into epilepsy and therefore be a positive rather than a negative aspect of using association members.

A second potential problem was that the membership of the associations included many people who were not directly associated with people with epilepsy, which reduced the possible numbers available for the research. This was not a problem for an exploratory study. The term 'caregiver' was a personal preference. References in sociological literature vary between 'carer' and 'caregiver' and the term most frequently used currently seems to be 'caregiver'. It refers to an unwaged caregiver in contrast with a waged caregiver. The term 'careworker' would more appropriately be used for waged caregivers. Participants could therefore comprise not only relatives but also friends or volunteers

Permission was obtained from the Board of Management and the Committee of Management of the respective organisations, and ethics approval was granted by the University's Ethics Committee. A request for assistance with the research was appended to a current update of information for the respective organisational databases. The survey was used both as a means of obtaining a research population and also obtaining demographic information about the sample. From these initial 210 questionnaires, 26 responses were received from caregivers, of whom 24 were willing to be interviewed (see Table 2). Caregivers were self-nominated; that is, anyone who perceived themselves as a caregiver was accepted as such. The responses included 3 people with epilepsy living alone. Respondents were later contacted by telephone to arrange a time and place for interview. All interviewees agreed to do this privately in their home.

**Table 2      Survey response data - total respondents, gender and relationship to person with epilepsy**

	Relationship to person with epilepsy		Total
	Spouse/parent	Other (self, partner, friend)	
Male respondents	3	3	6
Female respondents	16	4	20
<b>Total</b>	19	7	26

Before the interviews commenced interviewees were asked to read and sign a statement of informed consent and were given an information sheet about the project. Interviewees were aware that I had been a caregiver and this made it easier for me, as one of “the wise” (Goffman 1968), to establish a relationship with them. Two interviews went ahead in the presence of a person with epilepsy, one with the person present all the time and the other when the person with epilepsy arrived home early. The presence of the person with epilepsy was interesting as the interaction between the couple showed the kind of relationship that existed apart from the interview. The length of the interviews ranged from 1-3 hours. Each interview began simply, with an invitation to the caregiver to talk about their experience of epilepsy. However a list of topics which may have been helpful if the conversation stalled was also prepared (see Appendix B). The interviews were tape recorded and transcribed by the researcher. Tapes, research notes and typescripts were kept in secure storage during the course of the project. The identifier 'P' (parent) or 'S' (spouse) identifies this aspect of the relationship with the person who has epilepsy, for example Rosemary/P indicates that Rosemary is the parent of a child with epilepsy. Caregivers were given pseudonyms. These and other characteristics of the caregivers are referred to in Appendix A.

In practice it was necessary to conduct interviews in clusters according to region because of travelling, cost and time constraints. There were advantages and disadvantages to this. An advantage was that transcribing time was concentrated. As I typed I was more easily able to see similarities and differences emerging from the data and to conduct an 'instant' comparison between the interviews. A disadvantage was that it reduced the flexibility of theoretical sampling since it was necessary to carry out two or three interviews in a short time. Typing my own interview material was valuable because it not only refreshed the memory of the interviews but I could visualise what had been happening as I listened to the tapes. It reminded me of the importance of tone and body language in the expression of emotion. Over the course of the research period I listened to the tapes two or three times each to refresh my memory of tone, pausation and other spoken effects. A journal was kept in which to record ideas, experiences, references and other material related to the research and this

also provided an account of the progress of the analysis of the interviews as well as an opportunity to monitor the overall progress of the research.

Each set of data was analysed immediately after typing and colour coded according to emerging themes. The transcripts were read several times each in their entirety in the course of coding and some sections were reviewed even more times to ascertain that my understanding of the meaning was consistent. Interviewing ceased when no new themes emerged from the data. This process is called 'theoretical saturation' (Strauss and Corbin 1998). This occurred after eight interviews were completed. This constituted one in three of the total caregivers who volunteered. Initial coding was further refined and re-examined to establish concepts that could form part of a theory. This set of concepts was then referred back to the literature on chronic illness, epilepsy and the emotions. The core category for these caregivers was the impact that epilepsy had in challenging ontological security, and this core category is therefore called '*ontological insecurity*'.

In the early stages of the research I read a great deal about epilepsy in an attempt to find information about caregiving. However, this literature search proved to be frustrating because there was very little information on caregivers of people with epilepsy (see Chapter One). Literature on chronic illness and caregivers in sociology and other disciplines was helpful but not complete. The literature review in this thesis represents the results of a number of consecutive literature searches over the course of the research. Under some circumstances a literature review is cumulative in the way one piece of reading material will lead to another and also because of the necessity to keep up to date with published research. However, it is necessary to follow new concepts and themes as they emerge from grounded theory, with a focus on this important literature as well as keeping abreast of current research, so the literature review proceeded concurrently. I used the available databases on the University computer system as well as the services of inter library loan in order to follow emerging topics and new research. It was not possible to read every entry. On *Medline* for example a search for 'epilepsy' yielded 16,481 entries between 1993 and 2002, for 'caregiver' and 'epilepsy' the search yielded three. So, instead, a modified

search using 'caregivers and epilepsy' as the search criteria was entered for all database, library and journal searches. This was refined to include combinations of 'caregivers', 'epilepsy' and 'emotion' as the research progressed.

Early studies of caregivers concentrated on the medical aspects of care and the burden and management issues of caregiving. However it is apparent that studies of caregiving, or caring, was not a high priority. A search of the university library catalogue showed that, of 287 books and articles related to 'caring', only eight were published before 1980. Of these three were concerned with the care of 'handicapped' and 'troubled' children, two with the care of the aged, one on staffing residential homes, one on the 'philosophy and science of nursing' and one on the hospice movement. A similar search of journal articles in *'Sociological Abstracts'* for 1963-1975 with the search criteria of *'care\* and illness and sociology'* produced only 31 entries, with three out of four articles on care focussed on medical professionals and only one on family care for the mentally ill. As the importance of emotion emerged as a significant factor in the analysis I began to read further in this area. In this way reading proceeded concurrently with the research.

This research deviated from the standard form of grounded theory because the interviews were clustered by region in the interests of economy of time and money as some participants lived seven hours from the research centre. However, the method of analysis and continual referral back to the interview data to verify emerging concepts did stick to the guidelines established by Strauss and Glaser (1975). The grounded theory method worked well. It provided the flexibility to follow up emerging themes and the opportunity to listen to what caregivers considered to be the most important aspects of their understandings of epilepsy.

By the end of the taping sessions a very diverse group of eight people had been interviewed, including caregivers from each of the three main regions in the state and from urban as well as rural areas. The experience of caregiving ranged from 18 months to a maximum of 30 years. Two caregivers had part-time work, one did some voluntary work and five were full-time caregivers. Caregivers were all articulate and



included at least two university graduates. Other characteristics of the caregivers are shown in Table 3 below. Of the eight people with epilepsy, two had West's syndrome, a relatively rare combination of epilepsy and physical and intellectual complications. Another person with epilepsy had had a major stroke that affected mobility and speech. Two people with epilepsy had seizures that were completely controlled. Another person with epilepsy often went into status epilepticus - a potentially fatal condition. Other seizure types included: Benign Rolandic epilepsy (sleep related), generalised tonic clonic and complex partial seizures (see Table 1). Some people with epilepsy were born with epilepsy, some had acquired it as a result of illness or accident. No males who were parents offered to take part in the research, and three males who responded to the request for help described themselves as caregivers in their own right (see table 2).

**Table 3            Interviewee data - location, age, relationship to person with epilepsy**

	Location		Age of caregiver		Relationship to person with epilepsy	
	Rural	Urban	Age < 50	Age > 50	Parent	Spouse
Male	0	2	0	2	0	2
Female	2	4	5	1	5	1
<b>Total</b>	2	6	5	3	5	3

**CONCLUSION**

In summary, the research has been based on an interpretive hermeneutic method within which I analysed unstructured interviews with eight caregivers. From the analysis I developed conceptual categories reflecting their experience and understanding of epilepsy, relating these categories to existing literature and previous studies of both epilepsy and caregiving. I conclude that the core category which best describes the experience of caregivers is ontological insecurity, and the following chapters show how this has occurred and discuss the implications for the sociology of the body, health and illness and the emotions.

## **CHAPTER 5 - ONTOLOGICAL INSECURITY**

If a central goal of social science is to understand the basis for social order in every day life it is often best to proceed by studying those situations where order breaks down, where normal interactions are thrown into disarray, where the normative arrangements surrounding relationships become opaque (Karp 1996: 162).

Epilepsy creates a situation such as that described above by Karp (1996) where life becomes chaotic. It sits on a fault line between wellness and illness (Crouch and MacKenzie 2000: 4), close to the realm of the unknown, the unexplained and the uncontrollable.

This chapter describes the emergence of fear from the breaching of protocols of the 'controlled body' and the revelation of a situation in which unseen forces operate. I argue that this fear and uncertainty underpins the construction of epilepsy for the caregiver. There are two principal components. First, I argue that the experience of seizures confronts the expectations of body security - both that of the caregiver and of the person with epilepsy - and that this fear of ontological insecurity remains even when the caregiver is accustomed to the seizures, or when the seizures have been controlled. Secondly, I argue that seizures disrupt the experience of time for caregivers, "*collapsing*" 'social time' and 'inner time' (Melucci 1998) into one whole, because the caregiver's relationship to time is dependent upon the occurrence, duration and severity of seizure activity. For caregivers, social time becomes non-existent, all time is inner time.

### **5.1 Ontological insecurity**

If, as Giddens says (1990: 92), ontological security is the 'sense of the reliability of persons and things, so central to the feeling of trust', then one consequence of the unpredictability of epilepsy is *ontological insecurity*, not only for the person with epilepsy, but also for the caregiver. It creates fear and uncertainty. This feeling of being 'on stretch', as Rosemary/P (caregiver and parent of a person with epilepsy, see Appendix A) says, applies whether the person with epilepsy is present or absent. It is a form of "*latent fear*" for the safety of the person with epilepsy, that is, the fear is

present but not acknowledged until a seizure occurs. Because a seizure may occur at any time the caregiver's ontological security is severely compromised. If social processes are put in place to control such situations, with epilepsy they fail. In these circumstances, caregivers experience ontological insecurity and resort to controlling what they can which results in imposed order. Ontological insecurity refers to the state of being where one or more existential beliefs are put in doubt and relates closely to the fear and uncertainty generated for caregivers by the experience of seizures. In this respect it differs from Karp's (2001) concept of emotional anomie which refers to situations of emotional turmoil experienced by caregivers of people with mental illness.

The first important relationship for the caregiver is with the person with epilepsy. The caregiver has typical expectations of the sick person which are connected with the proper control of the body, predictability of daily life and actions, caregiving (particularly preventing danger), and the expectation of social order. When these are breached fear and uncertainty are typical responses.

#### **5.1.1 Seizures and ontological insecurity**

Epileptic seizures breach 'situational proprieties' (Goffman 1963: 243) and are regarded as 'improper conduct' (1963: 216). The assumption that daily life and activities will continue consistent with acknowledged rules of interaction is threatened by epilepsy. The unpredictability of seizure activity, as well as the appearance of seizures, creates uncertainty in the security of everyday life, and subsequently fear, in the caregiver.

A seizure is the bodily equivalent of an earthquake or a volcanic explosion. No matter how much the effects are anticipated, the actual experience for the caregiver is always unique, idiosyncratic. Even the language caregivers use to describe a seizure is similar to that used to describe earth movements such as shiver, shake, flicker, drop, tremble, crash, bang. Not only does the physical expression of a seizure cause fear but also the accompanying unseen consequences such as possible brain damage, intellectual effects,

emotional trauma - which is even more terrible when the person with epilepsy cannot communicate well, or at all.

Fear emerges as a consequence of the experience of seizures. The expectation that bodies will behave in a socially correct way is one of the first expectations to be breached. Fear is experienced first when the caregiver sees a seizure, and is then exacerbated by the continuing threat of renewed occurrences. Andrew/S (caregiver and spouse of a person with epilepsy, refer to Appendix A) says "It's like living on another planet". The continuum of seizure activity covers a huge range from brief moments of blankness to critical life threatening events. Initially, the experience of a seizure is horrifying, not only because there are usually no warnings, but also because the appearance of a seizure is so bizarre. Gina/S (refer to Appendix A) recalls her reaction to the only seizure she had witnessed as a girl.

It was sudden, we weren't warned and it can have quite an effect, you know, particularly if they are frothing or vomit afterwards or whatever...so it's not a nice experience for anyone to have to witness.

However, not only can the pattern of seizure activity vary, but the type of seizure can change (refer to Table 1 for descriptions of types of seizures). A person with one type of epilepsy, for example, simple partial seizures, may begin to have complex partial seizures. Absence seizures may suddenly be augmented by tonic-clonic seizures. The intensity of seizures can alter so that the seizure may appear to be more violent or more troubling for the person with epilepsy. The number of seizures may also change so that infrequent seizures become daily or even several times daily. The caregiver cannot anticipate the intensity of the seizure, the type of seizure or the number of seizures that may occur.

### **5.1.2 The experience of ontological insecurity for the caregiver**

Once caregivers understand the implications of continued seizures, ontological security is not possible. Seizures symbolise an end to calm, and foreshadow unpleasant and often dangerous consequences, the precursor to disruption and damage. This is emphasised in this research by the reaction of Elizabeth/P, the caregiver of a person whose epilepsy is mild and seizures are exceptionally well

controlled. She says "It's trying to control my paranoia over her. I don't know what it is, yeah my protection over her." And, in one case, when only one seizure has ever been diagnosed and medication was given as a precaution, Gina/S says: "I think the epilepsy thing was just the kind of final thing, that maybe... you know it could be, and was, life threatening, and if it had continued I just didn't know what the outcome would be".

Even when the epilepsy is controlled by medication, the threat of another seizure is still omnipresent and although seizures may be very mild, fear is a constant part of the lives of the caregivers. As Andrew/S explains "...epilepsy is an insidious sort of thing because you can't really see it but it's there." In their study Crouch and MacKenzie (2000) describe a similar state experienced by people who have survived cancer.

### **5.1.3 Seizures as a symbol of fear**

It is important to note that seizures move from becoming the *source* of fear to becoming a *symbol* of fear for the caregiver.

Having the seizure you know that was fine. But yeah you know what are the effects after? I was more not frightened by the actual fit but what was going to happen after and how she would feel...that was more my worry...what are the effects after...are they doing more brain damage? (Terri/P).

Caregivers begin to regard the seizure as a precursor to, and symbolic of, other problems. They become aware that effects on the brain are not observable. This means that seizure activity becomes related to other aspects, for example, possible serious disruption to present and perhaps future life, because seizures represent not only apparent injury, but also unseen injury. In this way seizure activity acts as a catalyst to the fear of unseen dangers. 'You just don't know...what he's going to be like. Whether he's going to be a real vegetable you know this time when he comes out of it' (Mel/P).

Living with epilepsy is exacerbated by the lack of a 'career timetable' for caring for the condition. As Sandra/P says

I mean as horrible as cancer is, there's sort of - there's a certain path that cancer kids take, you know. Like they have this medication and then they do this and they do that and the stages and hopefully they come out the other end and sometimes they don't and it's fairly well much the same.

But when you have a kid with epilepsy it's just so much unknown you know, like the medication might work and it might not, and they might get better and they may not, and this one, this fit they had today might be fine, but tomorrow it could kill them and you know there's so much unknown and you know like I think if it was just, if you could have more access to the brain and understand it that would be wonderful.

Caregivers of people with epilepsy feel helpless because there is no epilepsy timetable, they are isolated from reference groups, and there is no illness career, in the same way as the patients in Roth's (1963) research did.

## **5.2 Collapsed time**

Another social construct that is taken for granted is the control of time. Lives are regulated and affected by temporal constraints in a way that is rarely appreciated. But even time is changed by epilepsy as the past experience of seizures impacts on the present and ultimately the future. The discontinuities of time create uncertainty. The irregular rhythms of the illness continually control the lives of the caregivers. They must adjust to a life which is always on guard against the possibility of a seizure occurring, where the person with epilepsy may be temporarily incapacitated or have to be suddenly rushed to hospital.

In this respect Melucci's (1998) discussion of time becomes relevant. Drawing upon the elements of inner time he describes, I argue that, for the caregiver of a person with epilepsy, "inner time" *becomes* "social time". For the caregiver there is no other temporal experience except that revolving around the possibility of epileptic seizures. The experiences of caregivers precisely describe the course of inner time. Caregivers experience this time in a symbiotic relationship with the cared-for. Using Melucci's (1998) temporal concepts of *cyclical*, *simultaneous*, *multidirectional*, *immeasurable* and *unpredictable* as a guide, events in caregivers' lives can be neatly described. In *cyclical time* events recur and repeat themselves in nearly identical form.

They got the oxygen lines going in ... and they were in radio contact with the hospital. They called for another person to come out you know, another ambulance as well to come out, because they didn't have enough ambulance people there to get him into the hospital. We've had to do that a few times. We've even had an ambulance leading the way (Mel/P).

For instance my first experience of disruption and totally disruptive to one's life was fitting, because I'd be knitting, knitting a pattern, and in the middle of a row suddenly she'd cry. And you'd have to go and pick her up and there'd be a fit with the crying quite often (Rosemary/P).

*Simultaneous time* is where futures are experienced at the same time as the present. Every seizure contains a fragment of fear of the future. Anticipating the future not only encompasses the distant future but also the immediate future. Fear and uncertainty created by seizures also leads to issues of safety not only for the person with epilepsy, but also for the caregiver. Caregivers also fear for their own lives if they have an accident and the only person present is disabled. "What's stressful? ...if something happens to me and he's here....whether he would actually be able to use the phone ...if I collapsed....." (Gina/S).

The prospect of the future is particularly frightening for the caregiver. In most cases this is expressed in terms of the person with epilepsy. Caregivers become aware of the lack of resources available to them as home caregivers and critical of a system that rewards them for placing their partners or children under state care, but gives them little for providing personal and loving care at home. There is no facility supplied for people with disabilities until they are ready for aged care. They fear that if they are not able to provide care that the person with epilepsy will suffer as a result.

I try not to think about it too much 'cause I think, I mean, in a house by himself, or you know, will he have children or will he work and what can he do but it's so hard to judge what he'll be like when he leaves school (Sandra/P).

I mean, what's going to happen? You're worried about whether, how normal, your child would be and we were also worried in those days about the future of our children (Rosemary/P).

But I couldn't bear for him to be somewhere where he's not constantly watched which is going to be hard because, I mean, there's going to come a time when he, he's not going to have somebody with him all the time which is a worry (Sandra/P).

In the event that the caregiver may become disabled or die the future of the person with epilepsy is uncertain. Sandra/P says "I sometimes really worry that if I died, you know, what would happen to him...?" and Andrew/S asserts, "But of course if I wasn't here or whatever, [the person with epilepsy] is certainly not going to be able to live here on her own and I'm certain she knows that".

The *multi-directional* quality of inner time, where time has elements of past, present and future, is illustrated by the way that Sandra/P talks about illnesses that frighten her because of her past experience. In this particular situation Sandra/P relates to the past where a fever led to her child's illness and applies it to every situation where her other children may be unwell.

It's the most difficult thing when they get sick...when [they] get a fever or something it is just terrifying, absolutely terrifying and it's really hard to control that you know...

When the perception of time varies from one moment to another, time becomes *immeasurable*.

Time to me is like ... we're nearly late every morning for school you know but like, ... [her] medicine's around eightish, while we're in the bath, but you know sometimes it takes 10 or 15 minutes to swallow. Or, you know, if she has a fit then it's slower and I think, well imagine trying to catch a bus and getting her to [town] at half past seven and things like that (Terri/P).

It was, it was the longest 12 minutes - oh and when they got here after they'd sort of given him some stuff and they'd given him oxygen and they got his airway going and he was still like not with it (Mel/P).

The unpredictability of epilepsy undermines routines and sets its own agendas.

That was another difficulty because suddenly this child would just go forward and you couldn't see because of the speed of the fall forward what she'd hit herself on. And it was living not only with epilepsy but it was living with an actual crisis



condition because anything hard around anywhere was potentially lethal virtually. You had to, you were dealing with crisis all the time and that really was difficult (Rosemary/P).

People just don't understand what it's like to be epileptic, live with epilepsy ..... They just don't know what happens in this house. But bang, there's someone falling out of bed at 3 o'clock in the morning, or bang, there's someone at the kitchen bench and suddenly on their back, you know with a bash on the head and a split nose or something (Andrew/S).

Where the experience of time moves to a different agenda, and affects social life and circumstances, *inner time becomes social time*. Even if the person with epilepsy has controlled seizures, knowledge of the uncertainty and unpredictability connected with the condition is always a factor. In effect, time collapses.

## CONCLUSION

Hochschild (1998: 6) makes references to an "emotional dictionary", which contains the kinds of emotions culturally available to a person, and an "emotional bible", which prescribes the cultural expectations of the situation in terms of emotions (1998: 7).

Most "emotional cultures" do not provide guidelines for the situations in which caregivers of person with epilepsy find themselves. They experience fear and uncertainty as they encounter the breakdown of order, normal interactions and normative guidance (Karp 1996: 162), because these are the only framing rules that fit the experience of epilepsy in their emotional reference library.

Fear is expressed by caregivers when they first observe seizures, which breach all rules of proper conduct. Although the experience of seizures becomes routinised, the fear of such behaviour recurring recedes but does not disappear. Together with a realisation that unseen further damage may be occurring, for the caregiver seizures come to represent both a physical and social danger to the person with epilepsy. Fear is also produced when norms related to proper caregiving are breached. The caregiver is held responsible by other members of society for the continuing care of children and partners. When the safety of the person with epilepsy is compromised then social

norms are threatened. Associated with this is the lack of an illness career or timetable (see Roth 1963) as a guide to the possibility of remission or cure.

The system of social order that provides stability of social life is a fragile one. Seizure activity challenges patterns of order by turning taken for granted assumptions of expectations of bodily conduct and social conduct upside down. This expectation is also breached because of the episodic and unpredictable nature of seizures. As a result the caregivers experience ontological insecurity.

Seizures also breach the expectation that time is ordered and dependable. This occurs not only when the caregiver tries to adhere to social time but also when other people do. Caregivers experience collapsed time where all dimensions of time are compressed into the present, and time is tied to the agenda of unpredictable seizures.

Ontological insecurity is the result of all these breaches of expectation. This leaves many caregivers in a state of continuing fear and uncertainty. Even those with the least to fear, live with the knowledge that this state can recur. Studies of uncertainty and fear show that usually such emotions cannot continue without damage to the person experiencing them (see for example Lazarus and Folkman 1984). Caregivers in this study tried to control their emotions using several strategies. Amongst others they institute protective measures, they use unobtrusive surveillance techniques and they establish rigid routines. But first they seek help from health professionals where they learn the limits of medicine. These are discussed in the next chapter.

## **CHAPTER 6 - RE-ESTABLISHING NORMALITY**

Ontological security ... indicates a primary and basic sense of security about being in the world, which underlies a person's capacity to engage in the business of living...the perception that...there is an order and a meaning to life (Davey and Seale 1996: 15).

Whenever major events occur which threaten ontological security, such as illness and death, this results in a disruption of daily life. The experience of seizures for the caregiver described in the previous chapter clearly represents a situation that must be controlled so that the caregiver does not experience fear and uncertainty. Surveying the wreckage of their lives, caregivers respond to the situation in socially ordered ways.

Ontological insecurity wrecks the illusion of safety that is created by social order. This chapter describes how fear and uncertainty are increased, rather than decreased, when caregivers of people with epilepsy turn for help to the institution developed to deal with illness. Caregivers question the status of 'expert knowledge' and begin to construct their own understandings of epilepsy and caregiving.

### **6.1 Caregiver understandings of medicine**

Since problems of bodily order have become the province of medicine, the usual response to a bodily problem is to consult a doctor, after exhausting other possibilities such as family, pharmacists and friends. The relationship with the doctor is an important one for the caregiver of a person with epilepsy, since very few options are available for treatment other than medical. The dominant discourse of the medical profession is that doctors are experts and that medicine can cure. This is reflected in the statements of the caregivers, particularly when cure does not occur. The doctor is specifically expected to have expert knowledge of the condition and medications, to be competent in illness management, to be sympathetic and supportive, to acknowledge the reports of the caregiver and to work towards the cure of the person with epilepsy. The experience of epilepsy highlights both the boundaries of professional skill and knowledge and the limits of the caregiver's willingness to trust.

Epilepsy demonstrates the situation which Light describes (1976) when he discusses the uncertainty that exists for doctors in the practice of medicine. Epilepsy is an illness where there is very little medical knowledge, where what knowledge exists must be applied on an individual basis, and where expertise is dependent upon a very limited range of medication or upon surgery in a few limited circumstances. Posner (1984: 155) describes a similar situation with her research on diabetes:

In many relevant areas [doctors] lack knowledge based on the firm foundations of statistically valid empirical research..... they have made it their job to treat a condition which they cannot cure and which may be degenerative.

Perceptions of the problem that health professionals and the health institutions have when dealing with epilepsy soon impinge on the confidence of caregivers.

Caregivers quickly learn that the condition of epilepsy is extremely idiosyncratic, so that doctors and other health professionals have to continually adjust treatment as they find out more about a particular patient's experience of epilepsy.

he'll look at her little chart that she does when she has a problem and he'll give her an extra half an Epilim at lunch time or a bit more of something else at night.....So the adjustment's there.....we always discuss what the sequence has been.....how many times has she had to have Valium during the month?  
(Andrew/S).

## **6.2 The significance of diagnosis**

The experience of chronic illness is a difficult process. Many aspects of professional behaviour and professionalism are threatened by it. People with chronic illness stretch the boundaries of medical care to the limits and this temporal expansion of illness allows patients to become conscious that doctors are not infallible. In many cases medical professionals are shown to be less aware of available treatments than caregivers, and in fact often know less about the illness itself.

The diagnosis is seen as a turning point in the life of the caregiver. Caregivers expect two things: that a diagnosis will be made and the condition given a name. For some

caregivers the diagnosis comes as the most devastating shock since it denotes not only the loss of future expectations for the person with epilepsy but also for the caregiver.

That was a terrible experience. We felt as if we'd been confronted with a death almost, that sort of thing. It numbed us, the reaction to it took over your whole life (Rosemary/P).

Terri/P says "I'd think - oh no!" when considering what she would have said if someone had told her what her life was going to be like. However, diagnosis may also be deferred or not given. If the doctor avoids giving a clear diagnosis, with its future implications, this leads to an even greater shock to the caregiver when the situation is later made clear by another health professional.

Oh the saddest thing I suppose is when I knew [his] developmental delay...was a lifelong thing and no one had actually told us that.....Oh it was almost as if he'd died, you know, all of the hopes you'd have for your child...well they're gone (Mel/P).

If the diagnosis is not made it creates another area of uncertainty. Caregivers are not aware if a lack of diagnosis is because the doctor can't give one, if it is because the condition cannot be identified, or whether this information is being withheld for some reason. The naming of a condition has been shown to be an important aspect of controlling illness (Murray 1993). Sandra/P says:

I wanted to have his epilepsy diagnosed. I wanted to know what it was but they just sort of said "Oh it's post viral encephalitis epilepsy" and that was that. So we've never been given a name for his epilepsy.

### **6.3 The importance of information**

Once a diagnosis is given patients expect that they will receive some information about the condition and if possible about the cause. Caregivers also need to have this knowledge to help them deal with epilepsy to manage their uncertainty and establish some control. People with epilepsy and their caregivers are not alone in finding that they do *not* receive information about the condition or illness as earlier research shows (for example, Korsch and Negrete 1968). Whether planned or not, the effect of having no knowledge of the condition is to disempower the caregiver at a time when control of fear is essential both for the well-being of the person with epilepsy and the

caregiver. It is possible that health professionals do offer information at the time of diagnosis but that this is not effective because of the effects of shock. For whatever reason, the perception is still strong that no information has been offered.

...he gave me no information whatsoever. I actually had to - I rang the Epilepsy Association and got all my information from them...I felt really angry afterwards because I felt that he should have given me the information... (Elizabeth/P).

...nobody sort of sat us down and explained to us anything about it and why he was so agitated and you know like that he was doing really stupid things. Nobody explained to us that the brain injury you know like it's common...we just thought that we'd been landed with this new [child] and we didn't know how to handle him (Sandra/P).

#### **6.4 Understanding treatment**

All the people with epilepsy in this study were being treated with one or more drugs. The pharmaceutical industry has grown in prominence and authority along with advances in medical science and the prescription of medicines is accepted as part of health care. Current "best practice" in the treatment of epilepsy is to get an accurate diagnosis of the type of seizure before giving any medication at all (Taylor 1996, Stodieck 2001). This is because some seizures may not be controlled or may even be exacerbated by inappropriate medication (for example, carbamazepine is ineffective when it is used in the treatment of absence seizures). However this "best practice" conflicts with the need to control seizures because control of "kindling" (establishing the tendency to seizures in the brain), is thought by some doctors to be a worse risk than prescribing an inappropriate medication. In such cases, health professionals, faced with continuing seizures, worried caregivers and patients, and no conclusive diagnosis, will usually prescribe medication anyway.

Medicines used for epilepsy have only recently received special attention. Until 20 years ago, anti-epileptic drugs were not very refined and had actually been developed to treat other conditions, mostly psychiatric. Then a new generation of drugs aimed more specifically at epilepsy was developed. These have since been refined further in an attempt to reduce unwanted side effects. However, little research has been

undertaken on the long-term effects of the drugs, and even less in such specific instances, as, for example, the effect of drugs during pregnancy or childhood, although research is extending into these areas now. As Elizabeth/P comments:

at that same lecture we also had pharmacists come down because I also wanted to know...the effects of the Tegretol on [her] schooling and everything like that you see and it seems to be very unresearched actually.

Caregivers understand that medications control seizures, and that, if they do, then the seizures will stop, and for certain seizure types, may never recur. However, caregivers also learn that medication for epilepsy may be hazardous, and that both side-effects and the cumulative effects of multi-medication are additional dangers. Medications are also known to be toxic and therefore must be given with care. Caregivers understand too, that over-medication as well as under-medication can lead to increased or worse seizures, that individual reactions to dosages are not uncommon, and that medication may become ineffective over time.

We'd put her onto one of the new generation 90's drugs called ...Sabril and that had caused [her] to have tremendous excitability and she carried on day and night screaming and yelling and shaking herself... (Rosemary/P).

Anyway I put up with it for the all of the week and then I just rang up ... and anyway I said ... "You've got to do something or I'm going to kill this child" ... and anyway he dropped it by half a mil, so I think it was up to 5.5, or was it 5, and it came back to 4.5, and you know she was a different kid within 24 hours... I just couldn't believe it and yeah it was just like (gasp)and I've put up with this for like for you know, like for about three months ... and it was just like total nightmare (Terri/P).

When he was on the Phenobarb he was taking Nitrazepam and Lamotrigine the Nitrazepam was to help him sleep because the Lamotrigine seemed to hype him up (laughs) and he and he was on ... five at one stage and the poor little bloke must have just been it's a wonder he could even stay awake (Sandra/P).

Caregivers find themselves having to demand changes in medication for the benefit of the person with epilepsy at times when it is apparent to the caregiver that the side effect is directly caused by the medication.

We found we had more trouble with the medication playing up on...us. She just used to scream.....you know like all day and I was just at my wit's end. I thought "Oh I can't stand this any longer" and I went back to the doctor and I said "it's got to be the Epilim". "No, no, no, it's not that" [said] the GP (Terri/P).

The use of drugs is very dependent upon the doctor's knowledge and experience.

Caregivers believe that specialists have the most up-to-date information about drugs, but are willing to negotiate or even disagree about what drug is being prescribed.

Treatment usually comprises advice about medication and management. The caregiver sees that the doctor's experimentation with drugs often has varying results because of individual tolerance levels.

He was going along really well and we'd sort of upped the Lamotrigine because he'd been stopping after 20 minutes, so we went over the safety limit from 300 mgms and took 350, and thought well maybe the Lamotrigine's the one but just not quite enough. Yeah so we took it. ... he had a fit, a complex partial ..... and so I called the ambulance after 15 minutes because I thought he might not stop (Mel/P).

Increasing knowledge assists the caregiver in developing confidence in the use of medicines. Caregivers use this confidence to challenge a particular course of action or use of drugs.

We found that Tegretol had become the ... primary drug for epilepsy and we'd never used it, so I confronted him. Once I would never have done that (Rosemary/P).

In the finish ... I had to take her back to [the specialist] again and he said she could take up to 12 of these tablets but he hadn't told us that in the beginning. And so she's still not settled down, she's still not completely settled down but her attacks are not severe (William/S).

However if caregivers feel that they are part of decision-making in the prescription of drugs, even if the medication does not appear to be therapeutic or the range of medications incomplete, they remain confident in the doctor's treatment of the illness and even attribute responsibility for an oversight to themselves.

I said to him "Why didn't you give this to us before?" And he said "I didn't know you went through this" so there was my poor communication. We thought because she was on Epilim because she was on Rivatril and Dilantin and whatever else, that that was it for epilepsy. And so silly us, we went through probably all



those years - I don't know how long Valium's been around but I guess it's a fair time - but I just always thought I have to stay home from work or be late for work or whatever while she came right (Andrew/S).

Although caregivers often have a strong liking for their primary health professional this is tempered by a pragmatic acceptance that the advice they are given may be inappropriate and they seek confirmation from other sources or disregard the advice altogether:

It was just like total nightmare. So then I've always been really nervous when they've put [the dose] up.....and the first sign of [hyperactivity]...then I tend to drop it back ...you know, a fraction would make that much difference! (Terri/P).

### **6.5 Medical training and uncertainty**

Fox (1957) finds that three main kinds of uncertainty exist during the first years of medical training. These are 'incomplete or imperfect mastery of available knowledge', 'limitations in current medical knowledge' and 'difficulty in distinguishing between personal ignorance or ineptitude and the limitations of present medical knowledge' (Fox 1957: 208). Light (1976) reports that another two more general kinds of uncertainty exist. He describes the uncertainty of both physical and psychological patient response to proposed treatment, and also uncertainties that are created within the organisational setting, including institutional arrangements and other doctors. The main sources of coping with these structured uncertainties, according to Light, are acquiring knowledge and working closely with others. The central problem he says is the need to act in the face of uncertainty. Light says that 'sociologically a profession's greatest need is for control' (1976: unnumbered page).

Applying these findings to the treatment of epilepsy, the treating physician is very often placed in a no-win situation. About 40% of seizures are controlled by medication, 20-25% of people with epilepsy will experience occasional seizures (1-12 per year), and another 35% will experience more frequent seizures (Taylor 1996: 17). This results in a situation where, for the majority of cases, both patient and caregiver become aware that whatever strategy the doctor puts in place, the probability is that it may not work, or may not work all the time. The doctor can neither explain this

situation because of the lack of knowledge, nor consult with colleagues who can help, because they are in a similar situation.

The analyses of Fox (1957) and Light (1976) rely heavily on the identified variables of knowledge and expertise but neither recognise one other important area of uncertainty for health professionals who work in the area of the brain. Because of the importance of the brain for human life and the way in which it operates, it is almost impossible to discover with precision what happens inside the central nervous system. Unlike, for example, orthopaedics or cardiac surgery, the brain's processes are not accessible. Almost all experimentation must take place either on brains from cadavers or outside the skull. A small amount of information is gathered by probes, biopsies and the new scanning technologies, but most research must be carried on without examining living material, because of the very real risk of doing permanent harm with even the most simple procedure. This hidden aspect of epilepsy, which also applies to neurological and psychiatric conditions, illnesses and diseases, results in a paucity of information and a barrier to further inquiry. For health professionals this is another dimension of uncertainty that is not experienced by those who deal with more accessible and more easily understood medical conditions.

Training for uncertainty must also be associated with clinical pedagogy, and the structure of higher learning. Medical courses are organised around the principle of acquiring an overview of medical knowledge, in contrast with the trend to specialisation at a very early stage in the learning of other professions. It is not expected that engineers, for example, will need to know much at all about other aspects of engineering other than in their specialisation as electrical, structural, civil, mechanical, electronic, aviation and marine engineers. Lawyers are also guided into some area of specialisation after learning some general principles. The same could be said of teachers, nurses, accountants, sociologists, information technologists, in fact all of the areas where the amount of information has not only outstripped the ability of people to absorb all of the material available, but is also expanding and prone to increasing revision.

The structure of medical learning is based on a model that was in operation in the 13<sup>th</sup> century (Porter 1997), requiring a period of academic learning, followed by hospital experience. This supports a hierarchical structure of expertise. Academic learning relies on hospital practice to fill in the gaps. Since hospital based care usually deals with emergency and extreme cases the many types of seizures may not be experienced, particularly since many admissions are for emergency outpatient treatment or for specialised neurology treatment. One caregiver commented that he didn't think that a particular doctor had ever seen a seizure because of the way he spoke about it. It is possible. Taylor *et al.* (1994: 19) observe that the incidence of epilepsy is such that most GPs see only two new cases per year. Once again this may mean that some seizure types are new to them and may not be recognised. Most seizures are treated by specialists, but even then people with epilepsy do not necessarily see an epileptologist (a neurologist specialising in the treatment of epilepsy). Paediatricians, physicians and neurosurgeons all treat epilepsy. Even becoming a neurologist doesn't necessarily mean specialising in epilepsy, although the chances of seeing people with epilepsy increase.

Light (1976) argues that the issue for doctors becomes one, not of uncertainty, but one of control. The professional learns to display a calm, authoritative manner and an air of omniscience and omnipotence. As doctors become more experienced this manner is adopted with more confidence, because experiential knowledge is the most valued of all kinds of professional competence. Where there is a difference of opinion, doctors give way to the professional with the most experience in a particular technique. This "cloak of expertise" is part of medical culture. Doctors expect to behave in this manner and also expect that patients will accept this as part of doctor-patient interaction. Patients expect that doctors will be experts and accord them high status in part by virtue of this special knowledge

However as epilepsy is a chronic condition, over time, the "cloak of expertise" becomes transparent, and reveals that doctors do not know as much as the caregivers are led to believe. This in turn creates mistrust between caregivers and doctors and caregivers begin to rely on their own expertise, which is based on their own "local"

observation and knowledge. A sharing of uncertainty, although it would mean the doctor acting out of role, would be better for a long term relationship, particularly if the caregiver's knowledge was also shared. However doctors are trained not to admit incompetence or lack of knowledge and this makes the 'cloak of expertise' difficult to discard.

## **6.6 The process and status of non medical knowledge**

For many caregivers a diagnosis of epilepsy is their first introduction to chronic care. This is a situation for which they are not trained before the event and for which training is not given afterwards. Overnight, caregivers are expected to become experts not only in epilepsy but also in management and medical care. As part of the shift of services from hospital to home (Glazer 1988), caregivers become part of an informal health system: observing the person with epilepsy so that they can regularly report to the doctor. In comparison with health professionals, they are rarely given training to do this, although they may keep a seizure diary as Terri/P does. Caregivers must learn about epilepsy, in the first instance through close observation and comparison of events over time. Secondly they learn from other caregivers and "the wise". These kinds of learning equate with Light's identification of experiential and collegiate sources of learning for doctors.

Caregivers become expert through their continuing familiarity with epilepsy, combining past, present and future observations with deductive reasoning. This body of expertise becomes the equivalent of experiential learning in medicine. Caregivers learn from experience, as doctors do in their training, and they also learn from their "colleagues" in support groups and at information sessions.

You know...[the doctor] wanted to put her on an old drug...Diazepam?.....when they were really bad and I rang her up...and she said "no don't do that...you'd be better off with...another new one" (Terri/P).

I found a lot out about brain injuries from a lady up the road. Her young boy got hit by a car and that's where we found out [why he] is you know like he is now but given time he's not going to be so agitated and aggressive and doing all these weird things he's been doing (Sandra/P)

In this example, Terri/P is trying to establish a reason for the change in behaviour of the person with epilepsy, continually thinking of the problem during the interview and trying to decide whether the medication is the cause or something previously not experienced.

she's been like that the last month or so and ... the doctor knows nothing wrong so ... obviously it's just - so I was wondering whether it could be the Epilim because it's done it to her before but then again it just could be the West's so I don't know. I'll have to think about that one.

(later) ... it's only been the last couple of months. She'll have a really good week and then she'll have a couple of bad days. This morning she was really fine.

(later) But ...when I think of the epilepsy the Epilim I think well she's been on that for a fair while but she does it straight away. If it's going to play up with her it usually does it in the first month or so...I don't reckon it's that.

Caregivers also learn from previous experiences with health professionals and illnesses. Where caregivers find that a particular course of action is effective they disregard conventions and act on their previous experience. This may bring them into conflict with health professionals but it does not deter them from what they believe is correct:

Yeah so when eventually I learned all the lessons but I had to learn them the hard way and I wasn't going to do it with [her]. That's why I was positive with [her] you know, we had to straighten all these things out right from the beginning. But it wasn't easy. The GPs were very difficult ... (William/S).

He wasn't happy with that but I said "well I'm just not going to" I said "there's other drugs around and I don't want her like a zombie..." (Terri/P).

As they do this they are making judgements about the professional abilities and trustworthiness of their doctors.

Similarly to people with chronic illness in Thorne's (1993) research, disenchantment follows when caregivers and their families find that not only are doctors not able to cure the condition but they do not even acknowledge the far greater knowledge and experience of the caregivers. They become angry when they are treated in a dismissive

manner. Some caregivers report their frustration at health professionals talking down to them, as if they could not understand processes or procedures without some kind of interpretation. Further, they note that the doctor is unwilling to accept the caregiver's views on what works best for a particular person. They complain that little status is accorded to the explanations or observations given by caregivers despite the fact that caregivers realise professional accounts may be neither explanatory nor informed.

Doctors discount and ignore the caregiver's growing observations and increasing expertise.

I'd tell him about the fits and he didn't seem to be able to do anything about it. It was almost as if he didn't listen or didn't take in what you were telling him (Rosemary/P).

I had a lot of trouble to convince the staff at [the hospital] that she must have these tablets on time you see, otherwise they were going to have trouble with her.....and every time I went to her I had to say "has she had her medication?" and she hadn't had it. They'd locked it away... (William/S).

Health professionals discount the caregiver's experience of the condition, although doctors and nurses may have to be instructed how to recognise a seizure. Not only do they discount the experiences but do not appear interested in the caregiver's information at all.

When I went in last time ...[he] sat up and was sort of looking around and, oh it looked like he was looking around but he wasn't of course, he was like that (makes a pose), and [the nurse] said "oh look he's coming around". ... I said "No I don't think so". "Yes look at him, he's just sitting up there looking around". And I just looked at him a bit more and noticed he wasn't moving his right side at all, and then noticed that his head ... he couldn't move it round to the right at all it was just fixed over to the left. His eyes were just searching for objects and so I tell her "no I don't think he's right, he's not right at all". I said, "look at him". And I started picking out you know what was wrong with him and [she said] "oh well the doctor will be here in a minute" and she went off ... I was really getting so frustrated (Mel/P).

Like doctors, caregivers are gathering and using the knowledge from their own observations of the person with epilepsy, and collating this into a body of expertise. Knowledge and information provide a basis for the caregiver to deal with the present and to help to anticipate the future.

And sometimes she wouldn't [be able to take the medication in time] and she'd have a fit and then she'd have another fit. But Valium has been a real life, not a lifesaver, but a time saver and a quality of life saver (Andrew/S).

I think one of the most frightening things was that ... nobody could explain to us. Like they could say ... he may have epilepsy but we didn't understand (Sandra/P).

Caregivers learn how to make the best use of a health system which is not geared to chronic illness by accessing the most current knowledge of epilepsy and medications from support groups, the Internet, public seminars and other sources within the community. Elizabeth/P comments: 'I've tried to go to any of the seminars that are relevant. I try to stay in front of it all'.

However sometimes the situation can become overwhelming. One caregiver reported that she received so much information that she could not cope and had to ask a health professional to act as an agent for all the other sources of information and pass on to her what was relevant:

We were getting too much information from different specialists. We were getting information from special education...we were getting information too from the [hospital] specialists...and then we had our own doctor...then we were seeing...the ear, nose and throat specialist...and so ...I asked him [the paediatrician] to see [the person with epilepsy] and sort of take over .....and try and make some sense of it (Mel/P).

Gradually caregivers become aware, not only of their own increased knowledge, but also of the calibre of this knowledge compared with the doctor's. From this position it is only a matter of moving to a new status where they listen to what the doctor says about the person with epilepsy but then decide for themselves what course of action they will follow. In her extensive study of chronic illness, Thorne (1993: 88) describes families as feeling vulnerable, confused, out of control, frustrated and angry. She says that families shift to a realisation of their own abilities in dealing with the

condition and change to being in charge and being experts themselves (Thorne 1993: 190).

These feelings were supported by the caregivers in this study. In fact, in some instances, they discover that the health professionals know only as much as the caregivers or maybe less.

and of course they think that they know it all and they are telling us which is fine but I just think sometimes that their knowledge gap is quite big and they are trying to imagine what's happening because they are not seeing it and I think they have trouble coming to terms with it so we have to tell them what's happening (Andrew/S).

So I confronted him, once I would never have done that...but over the years I learnt to ask questions ... because every pronouncement he made about [her] turned out to be the opposite - wrong (Rosemary/P).

## **6.7 Relationships within the health system**

The expectations of caregivers with respect to the health system account for much expressed anger. It is more acceptable to vent negative feelings about an objectified other, than about friends or family who may have to help in an emergency. Criticism of health professionals and the health system is often expressed as a result of insufficient or poor care of the person with epilepsy. In some cases caregivers feel that the person with epilepsy is more at risk in the health system than at home:

They were really bad with the CAT scan actually because the radioactive dye that they injected - it took them five goes to get it into [her] arms and she was traumatic like you wouldn't believe... (Elizabeth/P).

I couldn't believe it. This doctor, there he is...and didn't even recognise that [the person with epilepsy] was seizing still and [the doctor is] saying he's all right! (Mel/P).

At the same time, the care and understanding of health professionals is warmly appreciated. Caregivers who have received emergency treatment or personalised attention are very appreciative.



I mean I know the problems they have a lot of problems with staff and things but every time like its been an emergency with [the person with epilepsy] they have been absolutely marvellous and I could not fault them, not once (Mel/P).

no I've learnt a lot about people who don't understand talking down to you and fortunately not medically well not out of the hospital system. In the hospital system yes but our private GP is wonderful it's an excellent practice ... and we feel that we're involved in any decisions and ... it's really good... it's great. I mean [our] GP is more of a friend and you know the staff know him[the person with epilepsy]... and it's good (Gina/S).

However, caregivers also criticise some professionals because of their lack of warmth. Elizabeth/P notes that part of this is also the result of the medical setting.

He was...very cold in the beginning.....he's very straight to the point, blunt..... maybe it was because I was so nervous in the beginning and he sat in this dark room behind this huge great big oak desk.

Health professionals are also criticised because they do not offer information about epilepsy or epilepsy management to caregivers or to people with epilepsy. This is seen by caregivers as part of the role of medical professionals and causes them to feel hostility when it is not done. The professional authority of health professionals is thereby not only diminished but the caregiver's ongoing confidence in their doctor's professional judgement is undermined.

In the situation where both parties are proceeding with the belief that they are at least equal in expertise, if not more expert, it is astonishing that more conflict does not occur. Although, as previously noted, all of these caregivers manage epilepsy with help and advice from the medical system, they reserve their right to seek out the best medical attention for the person with epilepsy, which may not be their primary health professional.

## **CONCLUSION**

The preceding chapter showed how fear emerges from breaching of expectations that the social body would behave appropriately and that the caregiver's experience of time would be as it was before epilepsy. Caregivers report how social expectations of a parent's or partner's role are breached when seizures challenge their duty of care.

They narrate how the notion of socially ordered time is exploded by the experience of epilepsy. Time is compressed, lengthened, cut short, vanishes or moves to a different agenda.

This chapter reported how caregivers in this study attempted to reconstruct their lives after the advent of seizures. Ontological security will be restored if the epilepsy is cured, and will be less problematic if seizures are controlled, but remains a permanent problem if seizures are uncontrolled. The experience of epilepsy is associated with normative rules which bind the person with epilepsy and the caregiver. In return the caregiver has expectations of reciprocal obligations from members of the health system. These obligations include cure or at least effective treatment, effective medications, the availability of an "illness career", information about the illness and advice on care. Breaches of these expectations surprise and shock caregivers, and over time, if not met, lead to anger. The temporal dynamism of group emotion may then lead to action to change social structures.

The health system becomes a minefield of contradictions for those who cannot be cured and leads to further uncertainty. Caregivers quickly learn to be "alternative experts" if the safety of the person with epilepsy is at risk, using newly acquired knowledge, experiential and intellectual, to assist them in their new role. Medicine does not provide an easy "quick fix" solution for epilepsy, and caregivers have to learn to live with the long term nature of their commitment. What this means for their lives is described in the next chapter.

## **CHAPTER SEVEN - THE CONSTRUCTION OF MARGINALISATION**

The relationship of ontological insecurity to altered understandings of the health system and the role of the health professionals do not inspire confidence in caregivers. Instead this experience confirms ontological insecurity for all but those who no longer have to worry about seizures and their outcomes.

However, uncertainty and fear results not only from the physical manifestations of epilepsy and encounters with the health system but also through day-to-day social interaction. Caregivers become aware that their social life has changed and that they are gradually becoming disempowered. Caregivers expressed awareness of the normative expectations that are part of social roles. They have internalised the duties and responsibilities of spouse, parent and caregiver of the ill. Caregivers, however, eventually come to regard the kind of "*sacrificial contract*" (Simmons 2000: 7) in which they have become bound to the person with epilepsy, to be one-sided. As part of this contract they expect social respect and gratitude to be given in return for their hard work and this does not occur. I will call this the "*caring contract*" to distinguish it from *sacrificial contract*, although the expectations are very similar: the sacrifice of part of a life-time in return for social honour.

### **7.1 The role of the caregiver**

The power of socialisation is nowhere more apparent than in the way that unpaid caregivers accept responsibility for the people for whom they care. Caregivers conform to social pressures of expectations which assert that parents, and particularly females, have a duty or moral obligation to care for the person with epilepsy. In the first instance socialisation processes guide young mothers into maternal caring (Ruane 1996), then as primary caregivers for children (Badinter 1981) and a growing role as caregivers for the sick, disabled and aged (Finch and Groves 1983). Males may also take on these roles but in far fewer numbers. Glazer's (1988) research reviews the appropriation of women's caregiving skills by the health sector.

## 7.2 Biographical disruption

Like people with chronic illness, caregivers experience "biographical disruption" (Bury 1982: 169) after epilepsy is diagnosed. Where once there was a solid belief that life would progress in some ordered, certain way, caregivers realise that this has changed. They feel this not only for themselves but also for the person with epilepsy. This is similar to the way lifestyle expectations are also reflected in first person accounts of people with chronic illness such as those recounted by Schneider and Conrad (1983), Charmaz (1991), Ezzy (2000) and Karp (1996; 2001).

Caregivers talk about these expectations of the future pattern of their lives and indicate how the realisation that their lives would be different affected them. The sadness felt by caregivers are most vividly shown in these accounts of loss.

[the doctor] said you know you always have this picture for your children. They're born, they go to school, ... they do this and then they get a job, get married and have kids, and you enjoy all that, and he said, you're not going to have that... and that was when [I] really sort of thought my goodness here I am with a 2 year old and you're telling me that now. You know like it was just such a shock because we thought it wasn't that bad at the time (Terri/P).

And we, naturally, as most parents would, had expectations of a normal competent human being when we originally gave birth to our daughter and we had hoped ... she'd distinguish herself in some way when she went on in life and none of that'd happen (Rosemary/P).

Yes but I think that probably the hardest thing to cope with is the fact that he was a very vibrant active person and sometimes I feel more like his mother. Yes it's not like being married. We sleep in the same bed but it's just not the same, but I mean he could be worse he could be a lot worse Thank God he's not. Yes but I think the difference is in the changes in the relationship are harder to cope with, but I guess I've accepted them (Gina/S).

Other caregivers show awareness of lost possibilities for themselves. For example when Andrew/S says 'I mean I could use the words challenge, and disappointment and lack of opportunities and financial opportunities missed and all that but that's not important', and Rosemary/P says 'I'd loved to have done a PhD and I've never been

able to do that, and I doubt I'll ever be able to do it', they are both expressing the knowledge that life may have been very much different.

### **7.3 Cultural marginalisation**

Caregivers are able to anticipate quite clearly how life will change through their knowledge of social values. They fully understand the kind of behaviour that other people will find acceptable. Some articulate the Australian cultural norm, in the same way that Andrew/S does: 'don't complain, don't explain'. Caregivers understand that the sympathy economy (see Clark 1987) provides limited support. This understanding creates a tension, with many caregivers wishing for greater public awareness but behaving in ways which perpetuate misconceptions and wrong beliefs. It acts to isolate the person with epilepsy and also to act as a barrier to other people who would benefit from learning about epilepsy. One older caregiver describes this complex situation. He does not talk about the epilepsy and the dangerous consequences of seizures expecting that other people will respect the way he is conforming to social norms. On the other hand he would like people to understand, although he acknowledges that there is no way they can find out unless he tells them.

People don't say you know how's your epilepsy today - it's just not one of those things. ....People just don't know, people just don't do that even though they know ... the thing we've found in the last months is that people just don't understand....They wouldn't have a clue what happened in this house in the last 24 hours or 12 hours or whatever and we just accept that. We're not going to go and say "oh gosh things have been really terrible you know [she's] had you know three falls in 6 days"... I think they will just want to get on with their life as we do and we just keep to ourselves (Andrew/S).

Another older caregiver reflects on her need for family support, acknowledging that part of the problem that her family does not help is because she does not let them know that she needs it.

but I think that all the family thinks oh you know Mum's just fine she's coping because I never let them see I'm not. Sometimes I might but it's just the way you either cope or you go under I guess (Gina/S).

#### 7.4 Stigma as marginalisation

A similar tension exists between the desire of caregivers to take part in social life, and the awareness that seizures would be seen to breach proper social behaviour.

Epilepsy has long been regarded as a highly stigmatised condition since most seizure types immediately place the person with epilepsy in the category Goffman describes as "discreditable". Anyone who is "discreditable" is potentially subject to various forms of social rejection. Caregivers in this study, although they didn't use the word "stigma" were aware of the potential for, and the practice of, social disapproval of a "spoiled" identity, although not all stigma was as overt as the situation William/S describes: 'they hadn't realised she had epilepsy and they'd been [there] with her for [quite a long time] and they did, they jumped back from her'.

However, caregivers do not always accept the right of the community to apply such labels. The interviews show a trend towards disclosure of epilepsy to others. This is in marked contrast to early studies of stigma. Only one person interviewed in this study reported a regular tendency to 'cover' for the person with epilepsy, that is to conceal the effects of epilepsy. The others had no reservations disclosing the condition in the interests of safety, although some had, and sometimes still did, attempt to mask physically distressing features of seizures to avoid distressing people unnecessarily:

We used to try and well not cover it (the seizure) up but it depends ... they kick and thrash a bit. A lot of people just don't ask, you know they just sort of look and just turn away. Or, I don't know where we were, oh out ...and [my husband] just said to whoever was beside him "oh she's just having an epileptic fit", and he went "OH RIGHT!" you know a look of horror. And we're just sitting there fairly calm trying not to make a scene of it. Yeah for strangers yeah they don't ask they just look (Terri/P).

People are affected by the presence of someone with epilepsy in that they are scared that there is going to be a fit. I hide her face when she fits and then they are not so scared ....Yes you get a contortion of the face that was quite gruesome at times so you can minimise the effect (Rosemary/P).

I just lock her in the arm there and we walk you know in unison with steps and we've, 6 or 8 times we've got home here...without her having a fit and people or the neighbours are saying "oh are you right" or people come along in shock you know wondering what's going on (Andrew/S).

Recent research indicates that people with disabilities and their families are becoming more resistant to stigma and disadvantage, and more militant in their requirement to be treated as 'normal'. Millen and Walker (2000: 5) argue that people with chronic illness are also beginning to 'remake moral meanings' and may not 'passively accept a less legitimate status'. One caregiver expresses the unfairness of negative social reactions from members of the public, although she now believes it is not her problem but theirs.

it wasn't a feeling for me it was a feeling for [the person with epilepsy] ... like those people who are looking at [him] like he's queer you know and as I say I got really angry about that and now I just think oh well if they don't understand it they don't understand you know (Sandra/P).

Other caregivers think it is important that people develop understanding and empathy with a person with epilepsy. One, who was adamant that people needed to be informed about epilepsy, also expressed another reason why understanding is limited, that seizures are not always public events:

Understanding and that's the most important thing. People must understand about it. But having never seen one of these major events (generalised tonic-clonic seizures) I think the more people who understand the better. ... Perhaps you know that's why I think the time's right now that Australians are willing to accept it ... Oh I'd like to see something done about it yeah... I know it's not easy to do it and people don't want to be embarrassed do they? (William/S).

## **7.5 Economic marginalisation**

That chronic illness limits the caregiver's participation in social life has been reported widely, with studies dating back to the 1970s (Blaxter 1976; Baldwin and Glendinning 1983; Fitting *et al.* 1986). These limits are structural, including not only economic barriers, but such things as transport arrangements and the conformation of buildings. Without social access caregivers report that they feel isolated and lonely.

The economics of caring for person with chronic illness usually means that families are economically disadvantaged because the caregiver is restricted to fewer hours of work, if able to work at all. The health system is dependent on the hidden labour of caregivers and the strong cultural expectations that families will keep providing care. Unless they are well off, or have excellent support systems, caregivers are usually excluded from full-time work. The experience of caregivers in this study supports the observations of others in this regard (Baldwin and Glendinning 1983; Cant 1994). Excluding the three retired caregivers, all caregivers were either not working or had some part-time paid or volunteer work. However, the retired caregivers indicated that they would have liked some outside work and other caregivers were aware that circumstances may force them to give up their jobs.

we'd like to keep [the person with epilepsy] home as long as possible. That's our choice that's what we'd like to do but with help. You know I still want to be able to work. We still want to be able to have a life (Terri/P).

One caregiver felt that she could not return to volunteer work, although she would like to, because her experience might make her an unsuitable person.

I might be rather rude to people you know, you know if someone was telling me something that was pretty bad for them and I might be judgmental (Gina/S).

Other caregivers report a stage when they had to give up voluntary work because of their feelings of envy and jealousy when they watched other parents with their children:

I'd sit in the classroom and I'd look at the other kids and I'd feel jealous because they were so normal and so I said "oh I can't do this any more" (Sandra/P).

I'd got to the point in grief and loss where I couldn't see normal children with their parents and the way they haggled and jostled to get their children in here and there, because my child would have no chance whatsoever (Rosemary/P).

Multiple disabilities mean more economic disadvantage, despite the support of government agencies set up specifically to assist by providing services, subsidies and small pensions. Caregivers are reluctant to ask for help which, even if available, may not be accessible to them. Extra costs apply not only to health care but also for



ordinary living, and when there is only one wage or a pension, even ordinary expenses mount up:

One bad fall about three months ago [the person with epilepsy] went flat on her face on the bathroom floor, which we had corktiled at the time, and ended up with two black eyes and so forth. So our GP ...made a suggestion to carpet it and it's been great (Andrew/S).

we know this house is too big for us - it needs some maintenance - but there is a lot of money that goes on the maintenance that [the person with epilepsy] was once able to do, so one day the week before last I paid \$180 to two people to do a couple of things (Gina/S).

## **7.6 Marginalisation by design**

Access is not only restrictive in the institutional sense. Disability theorists such as Mitchell and Snyder (1997) argue that many problems of access are problems because society is designed only for the healthy. Although town planners are beginning to provide wheelchair access in public places, home planners are well behind. Doorways and rooms are not designed to be inclusive. The absence of thoughtful planning of community services and facilities adds to the stress of caring. Caregivers report that social events, like visiting or picnics, become too difficult when wheelchairs or toilet facilities are exclusive to the "abled". Even the smallest details are a barrier as Rosemary/P observes 'when we go long distances you have to think about how to get into homes and people's houses'.

Something I did last year...was to organise flights for [us] to go [on a holiday]...and that involved me getting...pharmacies in the area...where we were staying where we could hire a wheelchair and a shower stool (Gina/S).

Although by and large, public architectural arrangements are adequate, caregivers point out that aircraft, for example, are not really designed for people with chronic illness and that most restaurants do not cater for special diets. Even a simple thing like visiting a toilet may lead to the caregiver breaking social conventions in order to attend to the person with epilepsy.

But often it takes two of us to steady her and...two people in a 'plane toilet would be just about an impossibility.....So you know you have awful problems. Or they

put the disabled toilet in the ladies and my poor husband has to follow me in or whatever (Rosemary/P).

Public and private transport also presents difficulties, not only of access or facilities, but also because of the possibility of seizures.

One of the other mothers was there...and she said [her daughter] used to travel to [the next large country town] on a bus and they wouldn't take her because of her epilepsy (Terri/P).

there aren't any disabled facilities on the train. How do you cope? Well we were very lucky the day we went ... this year on the train ..... she could have been very wet and we could have needed to strip her right through and completely change her. Well where do you do that? (Rosemary/P).

it's like a miniature drop fit - where she was violently flipped she now just gives way ... straight on to the ground. If she does that when you put her foot up to lift her into the 4 wheel drive that can be disastrous (Rosemary/P).

## **7.7 Isolation as marginalisation**

Sheer physical work also affects caregivers and restrains them from taking part in social activities. Nights without sleep, the stress of repeated seizures, the physical work and danger associated with seizures and the constant experience of being "on stretch" are all factors which make it easier for the caregiver to remain at home, although this means social isolation. The least stressed caregivers in this study were those with the support of close family networks and friends, or where the person with epilepsy was out of the home for several hours a day, for example at school. Especially prized were those occasions when some arrangement was made where they could go out socially from time to time or go on holiday.

I'm really lucky there...my sister had her on Friday night for the night and ...we always have like a weekend away ...just on our own twice a year and [my other sister in law] she'll usually have her (Terri/P).

The support of family and friends is critical in this regard because the safety and well-being of the person with epilepsy is paramount in the minds of caregivers. The assistance of family and friends is important to caregivers in several ways:

But if I hadn't had family around it would have been really really hard because like it was I still wouldn't feel confident leaving him with anybody that didn't know him. Well he wouldn't stay with them anyway (Sandra/P)

Her parents just accept it, you know my parents just accept it, my mother's very supportive of her. She's 85 and we go and visit her every week and she knows what we've been through and she's just very supportive (Andrew/S)

When family and friends cannot deal with the emotional or physical implications of epilepsy this is a disappointment and sometimes a cause of bitterness or distress for the caregiver.

I went to take [the person with epilepsy]...to visit Dad...and I was going to take him up for a treat and then I changed my mind because something happened.....I could tell though that he was actually relieved that I wasn't coming and bringing [the person with epilepsy] (Mel/P).

but hopefully apart from [family member] ...I think [the experience of epilepsy] has affected her a bit, or she thinks it's affected her and it may well be true..... and I don't blame her for that if she feels that, but again she doesn't live here and she doesn't really have to (words indistinct) ... (Andrew/S).

However, social access also depends upon either an event being accessible for people with disabilities, or upon alternative caring arrangements for the person with epilepsy. Outings with the person with epilepsy are often difficult because of the possibility of seizures and the caregiver's awareness of lack of understanding on the part of onlookers. Although attendance at functions or events without the person with epilepsy was acknowledged as a possibility it was rarely done. Caregivers describe the difficulties entailed in going out even for a day trip or attending social functions.

If you go out anywhere and it's going to be a day thing you have to take medicines because you don't know where you're going to be when the medicine's due... (Rosemary/P).

I had to come home during the evening before they cut the cake and make sure he was OK and he got himself off to bed and I went back and that was really sad because we needed him there but he just wasn't capable of being there ... in those days he got really, really tired (Gina/S).

Studies of the person with epilepsy emphasise the social aspects of having epilepsy. Researchers show that the impact on identity and social inclusion is lessened when the lives of people with epilepsy have the least disruption (Schneider and Conrad 1983; Scambler 1989). This has been shown to be the same for caregivers. Where social support is available so that caregivers are able to take part in their usual activities, feelings of isolation and emotional stress are much less (Hurdle 2001). The findings of this research support those studies. Where caregivers could put their duties aside for a time, they were more relaxed and confident than those whose families were not able (or did not choose) to support them and where part-time work was not available or accessible.

Caregivers realise over time that their lives are being altered by epilepsy. It has the most impact on those where the epilepsy is not well controlled. In the early stages the first sign that their social world is changing is the effect that epilepsy has on those closest to them. Family members may not be able to cope with the effects of epilepsy and may withdraw their support. The experience of unfulfilled social expectations, and ongoing fear and uncertainty, has a big impact on the lives of caregivers. They also recognise that any kind of unusual behaviour is also treated as 'breaching' behaviour and social sanctions apply. Social existence is dependent upon an understanding audience and an understanding audience is not always present, with the stigma of epilepsy often overt and always perceived to be present. Caregivers find that major institutions such as medicine and education do not have appropriate mechanisms in place to deal with those with special needs and that the physical arrangements of social life are geared to those with competence in movement and cognition.

## **CONCLUSION**

Instead of receiving social honour, caregivers find that the social institutions that support people with acute health problems become obstacles to the health care and normal expectations of people with chronic illness. Chronic illness stretches the ability of people to cope with such obligations because of uncertainty of outcome, indeterminate progress and the length of the illness. Each of these factors reinforce the

feeling that people with epilepsy and their caregivers are excluded from the “normal” social world. The familiar reactions of intimate others, interaction with the representatives of large institutional structures, the rights and mutual obligations of living in society are all destabilised by the experience of epilepsy. The social world of the caregiver becomes an arena of uncertainty, conflict and stress.

Caregivers discover that they are marginalised concomitantly with people who have epilepsy and that they have to learn to live in a world which is not designed for people with special needs. The social world thus becomes an additional source of ontological insecurity, with taken-for-granted relationships put at risk. The next chapter shows how caregivers react to the challenges of marginalisation.

## **CHAPTER EIGHT - RESPONSES TO MARGINALISATION**

To the most rational of civilised men health, disease, the threat of death, floats in an emotional mist, which seems to become denser and more impenetrable as the fateful forms approach (Malinowski 1954: 32).

Caregivers do not always meekly accept their circumstances, although some do. In this study two of the older caregivers were more accepting of their circumstances, although they expressed awareness of their marginalisation. This chapter discusses the emotional reactions to situations for which caregivers did not accept blame, and in fact, held social structures accountable. If this meant that they had to step outside a passive role then they felt that this had to be done. The strategies they put in place to claim their expected support are described with particular reference to perceptions of danger, efforts to return to a “normal” life and their relationships with institutions apart from medicine. In order to live with uncertainty, life must be returned as much as possible to the way it was before. To achieve this end, caregivers even step outside gendered and caring roles and challenge the authority of institutions.

Epilepsy creates uncertainty in a previously ordered world, the equivalent of Malinowski's 'emotional mist'. As a result of the accumulated disturbances that impact on ontological predictability caregivers make heroic efforts to re-construct their lives. Trust in the usual social routines and practices is shattered, and the uncertainty created begins a loop in which fear and uncertainty are linked. Uncertainty is generated primarily by the unpredictability of epilepsy and reinforced by the failure of social mechanisms to reduce uncertainty. Seizures break into periods when the caregiver thinks that the epilepsy is under control at last and re-confirm insecurity. Mel/P says “ Oh that last one it took us out of the blue and we thought we were getting there and but it's just scary”.

This research shows that caregivers create strategies that enable them to cope with fear, uncertainty and doubt and establish a process of re-constructing futures. One aspect of reconstruction is to discount the physical experience of a seizure and then to deal with the dangers associated with its aftermath. A second strategy is to establish

routines and procedures which make life as predictable as possible and form the framework for a new life. Part of this strategy is also to normalise the experience of epilepsy so that it becomes an expected part of everyday behaviour. The third strategy is to attempt to change the social structure to accommodate both the person with epilepsy and the caregiver, instead of marginalising them. This includes the possibility of acting in ways which caregivers would normally have considered subject to social sanctions, both from the viewpoint of others and also in comparison with their previous behaviour as parents or partners, even to the extent of becoming rebels. These strategies are discussed in relation to the aspects of social structure which provoke them.

### **8.1 Dealing with danger**

The experience of seizures can be compared with bombs dropping on ordinary citizens during a war, when there may or may not be a brief warning before a crisis occurs. Just as in war, citizens become accustomed to the process of dealing with bombing, caregivers become accustomed to the physical appearance of seizures. Life must go on and one cannot act if overcome by uncertainty and fear. One part of the caregiving process is trying to anticipate seizures, another is to establish a way of handling the crisis situation as it re-occurs and a third is to learn how to deal with the consequences.

The safety of the person with epilepsy is the primary concern for the caregiver. This means that caregivers are always alert to the possibility of a seizure and have to plan their lives to take this into consideration at all times. Learning to include the need for medication is important.

It's just a matter of remembering if you're going to a lunch somewhere you've got to remember to take [medicine] and all those sorts of things (Elizabeth/P).

The things you have to be so rigid with you know like the medications and ... as soon as he's out of the car or out of the seat you're always conscious of the fact that oh yeah [he's] out there wandering around and you know like we don't let him go outside by himself like there's always somebody there to keep an eye on him (Sandra/P).

As another example, Andrew/S says 'I always carry the valium with me ... in my pocket with a little bottle of water'. Even if epilepsy is well-controlled, caregivers continually try to anticipate danger:

I mean if [she's] going to stay overnight somewhere I will explain the situation to them and what to expect and everything and then I give them the option that if they don't want to take the responsibility she can come back home with me (Elizabeth/P).

It is also necessary to learn to have great sensitivity to physical movement, tone of voice and the person with epilepsy's manner of speaking. In most cases unobtrusive but continual observation of the person with epilepsy is necessary to ensure safety.

Other times she'll be just sitting in the chair and I'll hear it in her voice, the hesitancy, and I'll say "Are you right?" and she'll say "Yeah, yeah I'm all right". And so I'm just watching, and the next minute she'll be writing and the pen will go like that [shows action] and I know, well time [for her] to have a valium... (Andrew/S)

The caregiver's fear is also expressed in terms of overprotection of the person with epilepsy. They acknowledge the desire of the person with epilepsy to be as independent as possible, but it is difficult for caregivers to reduce surveillance.

Elizabeth/P says '...I do have to be very careful and try not to smother her too much .....she needs a little bit of freedom and responsibility'. Andrew/S shows the same concern:

...We try not to sort of live on top of each other.....I'm not going to sit in here and watch her like a hawk for I know if she's been a bit flickery this morning, or if she was at 3 o'clock this morning, I wouldn't sort of go too far away when I'm around the house...

If a seizure occurs, caregivers may discount some of the minor physical consequences of seizures so that their attention is focussed on changes and more extreme consequences of seizure activity:

Like, having all these fits - she's had a lot of falls....she'd be standing at the table and fit and fall backwards (Terri/P).

She's had a few smacks around the face and black eyes and broken noses and cracked teeth and stuff but that's about it (Andrew/S).



But that's the only effect ... when she gets tired she has a shudder, and if the shudder's bad enough she's laid up for 2 days...she's got to sleep it off (William/S).

However, not all caregivers are able to do this, particularly when the consequences indicate extreme danger. This particular caregiver has not become desensitised to the physical appearance of the seizures because they are so often life threatening.

...and I don't see how you get used to it. I wouldn't go nursing because I couldn't get used to it. We've been down in emergency and...they've had to put [him] right out to it, put him on the ventilator...and that's been absolutely terrible, absolutely terrible (Mel/P).

Finally, caregivers, in responding to a situation that is a crisis, may also have to use emotion work, by controlling their fear, in order to get the best possible attention for the person with epilepsy. Mel says: 'I managed to ... give them a short history so that ... the ambulance guys knew what they were dealing with'.

Another way in which the unpredictable is faced is through safety measures which insulate the person with epilepsy, and sometimes the caregiver, from danger:

Something that has been good for us has been the call centre, the Red Cross call centre. That's taken a lot of stress from me being at work and not knowing what's happening here. So we have that set up to just a normal cell phone and if [she's] feeling funny during the day, or she's had a tumble, she just hits a button and I can be home here within 15 minutes (Andrew/S).

Emotional stress is one of the most difficult things for people to handle. Fear, in particular, is often managed either through practices such as magic rituals or religion. In Western society fear is often managed by science, which is, in the case of illness, represented by the health system. The principal goal for caregivers is the hope of a "magic cure", a medication which will stop the seizures and restore life to normal for the person with epilepsy, or alternatively, knowledge which will allow the course of epilepsy to be managed in some predictable way. When this does not occur, the caregiver's experience of epilepsy is a constant struggle with fear and uncertainty, dealing with the unpredictability and the danger, adjusting to the time-altering agenda of the condition and overcoming existential uncertainty.

## 8.2 Frameworks for a new life

For caregivers of people with epilepsy the experience of seizures locates them in a dimension where social practices which normally regulate uncertainty are not effective. This means that they must incorporate routines and special practices to offset as much of this uncertainty as possible. This may include the necessity to organise as much of the day as possible:

So that's what I mean you ... you need to be a little organised. Lunches done and all that the night before and just ready to put in the bags and everything else done (Terri/P).

I did my tea at quarter to seven this morning. I still do it because I never know what I'm going to, you know, I mean now she's so good and most of the time if she's really upset I put a video on, but I still always think well I never know what could happen when she gets home at three, so I won't have time to get tea, so it's all done. It's all ready. So I do it every morning. At half past six this morning I said Mark what do you want chop suey or... something else? (Terri/P).

While others need advance notice of alterations to their routine so that they can make adjustments without jeopardising other aspects of their life:

I just like to know when people are coming so that I can organise myself around that. I really need to know what's happening and I use a daily planner and I use the calendar and I have to have a routine (Gina/S).

Caregivers try to use strategies of “normalisation” to attempt to ameliorate the issues of exclusion and stigma experienced by both caregiver and person with epilepsy.

Robinson (1993) identifies strategies which families use to “normalise” their lives around a person with chronic illness. She says (1993: 14)

There appears to be two ways that the evolution of the story of life 'as normal' is supported. The first is by minimising the size of the problems associated with the chronic condition through selective focusing of attention.....The second is by reconstructing the reference points by which the experience is judged.

Both strategies are used by the caregivers in this research. Andrew/S gives an example of reconstruction of reference points as he looks back on his life:

yes we've had to give consideration to epilepsy ... it's just been fantastic the way we've just led a *reasonably normal ... family life*, with our ups and downs of course

with kids and so forth, but I think it's made us fairly tough and we always say that there's someone worse off than ourselves when we see people in wheelchairs, or one leg, or kids who are deformed, or whatever. (my emphasis in italics)

Any improvement in the person with epilepsy's condition is also movement towards perceived "normalisation" of the condition. The response of the person with epilepsy to the caring given to them is really important to the caregiver. An attitude of co-operation and/or wanting to recover is the expected response of the 'sick role' and is appreciated by the caregiver. So, too, are achievements that indicate progress towards normality no matter how delayed or how small. When the person with epilepsy cannot communicate well the attainment of physical goals is often the only sign that care is being rewarded:

I started talking to her, giving her information about what we were doing, where we were going, and this sort of thing. And it was like hitting your head on a brick wall. There was no response. She had a complete blank on the face for years actually. So when that happened [an indication that her child actually understood what was occurring] it showed me that what I was doing was worthwhile (Rosemary/P).

But it's always been her favourite toy and she'd never really get back to putting them [the pegs] in. And last night we were sitting there all playing and she was actually putting them in the holes and of course she's grinning you know she's ...And we're all sitting there going [clapping] oh wow and she kept doing it yeah, just little things like when she achieves things (Terri/P).

But even for those with good communication skills, improvement in physical skills is highly valued.

In her crossword, she does a crossword every day, and you couldn't - the writing would just be like that [wobbles in the air] you could barely make the letters out. But I noticed yesterday with the crossword in the paper that the writing was just beautiful so it just goes to show that the clash [of drugs] was causing this tremor (Andrew/S).

He used to be very involved in what went on in the house and I think that if I hadn't encouraged him he'd still be sitting... it's a matter of having to help someone get back to do the things they used to do because he used to, he was a better cook than I was (Gina/S).

### 8.3 Activists and Advocates

Caregivers try to use strategies of normalisation to attempt to ameliorate the issues of exclusion and stigma experienced by both caregiver and person with epilepsy.

However, over time, it becomes apparent that this is not sufficient. Thorne (1993: 60) says that some patients and families whom she interviewed saw 'normalcy' as a '...double edged sword, a philosophy that can have beneficial consequences under some circumstances but crippling ones under others'.

As more and more institutional and social barriers to full participation are made apparent, caregivers experience more exclusion. As a result caregivers become alienated, and either react in ways which others regard as anti social, or become even more isolated. Caregivers react to continual marginalisation in ways which cause them to step outside accepted social roles. They challenge marginalising practices by becoming activists and advocates for the person they care for. Caregivers report that having to be an advocate for a person with epilepsy changes their behaviour:

You know when I first had [her] I was a shy little person, very quiet, and it's only through this that it's made me so talkative I've had to come out of myself and exert myself (Rosemary/P).

Rosemary recounts how another caregiver found herself in a position as spokesperson for a group:

And one of the parents ...put a wonderful case forwards and this wonderful woman you know, I'll never forget our admiration for her and what she did... I mean you get a person from the grass roots saying just in the way she said it ... she put it over that we needed, our children needed, more services in the school and we were pushing for physiotherapy and OT and work on the children's bodies because that was desperately needed.

The Education Department assesses each child on a case by case basis, which means that teachers can become stressed by numbers of borderline intellectually or physically disabled children. Only children who have an IQ of less than 50 are deemed eligible to have a special aide and epilepsy is not usually regarded as a sufficient disability to warrant special care. In one instance, a parent fought to get her child's life-threatening epilepsy first of all accepted as a disability (which meant an aide could

be appointed), and then to have the child treated as part of a group of similar others, and not as one child singled out for special attention. Describing her battle in epic terms, Mel/P says:

Then I had to go to the, to the discrimination [area] to get a lawyer ... and follow it through because I said to them that is just discriminatory because ... you're singling him out for someone just to follow round and watch him..... I said it's making him, you know, making life awful for him.

The expenses involved in caring for a person with chronic illness result in caregivers becoming critical of the economic benefits available through the health system. It is sometimes difficult for a caregiver to accept that expensive government services can be provided for hospital and institutional careworkers when there is very little money to help one caregiver do the same work at home:

just generally being a carer and receiving \$79 a fortnight for saving the Federal Government \$86,000 a year for keeping [the person with epilepsy] out of [an institution] (Gina/S).

or to provide what are generally regarded as necessary public facilities:

I know that lots of parents ... you know, they're wanting money from the Government to help look after these kids at home and yet if we all said tomorrow ... you take them and put them in an institution it's going to cost them twice as much money (Terri/P).

Children with epilepsy are often admitted early to school and retained as long as possible. Presently, there is no special arrangement for young adults with intractable epilepsy apart from living at home (perceived as socially restrictive), living in group homes (perceived as dangerous) and living in aged-care facilities (perceived as entirely inappropriate). Parents consider the best solution to be the provision of community facilities which continue the social experiences provided by schools, but to keep the person with epilepsy at home as long as possible. This may involve using legal and other community support to create a suitable environment. Rural caregivers are particularly disadvantaged with regard to special facilities. Terri/P says:

We've got a committee for a post-18 [structure for education or training after leaving school] hopefully 5 years down the track. Some sort of end up with a group home and a sort of a day centre with - like we know there are so many

needs. Everyone's different, they've all got different needs, but you know we should be able to get some sort of funding.

Since schools represent an institution where children with epilepsy spend a great deal of their life, the selection of a school is done carefully, even to the extent of moving to be closer to a particular school where the support of people with epilepsy is seen to be better. Rural schools seem to have more funding available for special care than city schools and smaller city schools are recognised by caregivers as better from a caring viewpoint than larger ones because members of staff know all the children. The availability of teacher aides and such specialist services as speech pathologists, are also valued.

We... did look into different schools for him wondering whether being in a mainstream school was a good idea but he was too able-bodied for P\_\_\_\_\_ and St Z\_\_\_\_\_s probably would have been the place for him to go but they don't get as much aide time and I couldn't send him anywhere knowing that there wasn't somebody watching him (Sandra/P).

The social benefits of integrated education for children with epilepsy were spoken of highly by caregivers who were parents. It is seen as both beneficial to children with epilepsy and to the general school population to have the students mingle with students who represent the full social spectrum of abilities. The caregivers report many examples of the caring attitudes of students, aides and teachers.

We'll go mad - they'll go mad you know because they're so used to having the social, you know, Sarah really enjoys the kids and yeah and that sort of like, you know I mean she's at school (Terri/P).

Negotiations with institutions like schools are not always straightforward, and sometimes require caregivers to step outside their usual roles.

You see we were saying what will happen when our children become adults, they'll be up at [a mental institution] you know, that was the big fear in every parent's mind in the chat group.....Yes so we called in people who we felt could push for our concerns and the chat group later became S\_\_\_\_\_ ...so we started pushing for better conditions for adult disabled people and ... we called a politician in (Rosemary/P).

There is a gradual realisation that many aspects of daily life are not designed for those with disabilities. Because the logistics involved in moving people with disabilities continually stress caregivers, members of the public who make it difficult for them by parking carelessly, or cause anger, by criticising caregivers for using disabled facilities because the epilepsy is not obvious.

The lady said "Look park down the side that's fine". So it was raining last Friday night and I went to park down the lane *and someone had parked over the driveway*. Gee I was ... I had to get [her] out in the pram in the rain, ... and walk down the street and come, you know, like in there five minutes and come back again, and yeah I just think oh that's when I'm really annoyed with people (Terri/P, my italics).

Had a couple of comments by people seeing us in the disabled bays which really annoyed me... because he looks absolutely normal other than being a little bit overweight ... so that was ... a bit testing (Sandra/P).

#### **8.4 Burden of care**

The work of caregivers is constant (Corbin and Strauss 1988, Finch and Groves 1983, James 1998, Karp 2001). Since it continues without such benefits taken for granted by careworkers as a fixed working week, overtime, flex time, public holidays, sick leave, holiday leave, stress leave and debriefing after crises, the availability of respite is another aspect of caring that causes uncertainty and anxiety. Caregivers often need emergency respite, for example when they or family members are ill. Despite the hard physical work of caring, the management problems and economic worries, more often they require respite just to escape the emotional stress of caring.

I'd spend more time rocking in that chair than any time...she'd just be screaming and I'd be rocking, rocking, rocking...it was a total nightmare, it was a blur you know, you can only remember bits and pieces of it (Terri/P).

Until recently, the only state-provided respite care available has been designed to care for the sick person in a respite centre or to have a qualified caregiver coming into the home. Caregivers of young children object to this. They are concerned about the effect on the child with epilepsy and also about the safety aspects of caring away from the home. In their opinion a stressful situation is made worse by moving young

children out of their home environment or leaving them with a stranger. Although respite may be needed urgently, it is not requested if it is not appropriate.

There is a safe house we can take him to...and leave him there...but we weren't too happy with that...because [the person with epilepsy] has such limited communication skills and...it could be difficult (Mel/P).

We looked into respite but I couldn't do it. I just couldn't. You know like seeing that he's so comfortable where he is...I think he would be sort of frightened even after a getting to know you sort of period...I don't think he'd cope well with it so that's ...out of the question (Sandra/P).

Family members are the preferred alternative caregivers. Their practical support in the form of respite care or taking over household chores during especially traumatic times is a particular benefit to caregivers.

Mum and Dad moved up.....they actually moved up to help us which was wonderful because Mum was one of the few people that he'd go to...to give me a break...my Mum and Dad are about 10 minutes that way and my sister's about 5 minutes that way (Sandra/P).

Work also represents respite for the caregiver because it provides emotional relief. Whether voluntary or paid, part-time, full-time or casual, it is valued as a means to escape the rigours and responsibilities of caring or as a way for mutual "space" for both caregiver and people with epilepsy.

It just gets you away from the everyday, you know the normal routine. You get to work and you sort of forget. Oh you don't forget but you know .... there they don't talk about [her] and things like that so I don't have to (Terri/P).

I go Tuesday and Wednesday and it's good for us because it does give us a break...so we always have something different [to say]...so it's been good, so I've been doing that for 6 and a half years ... [and] while I'm fit enough to work well I think I'll continue (Andrew/S).

Part-time work can also represent an economic benefit that offsets the extra cost of caring for a person with a chronic illness. However this is not the main benefit for the caregiver, and in any case is not always possible:



I don't seem to have any other interests and I guess I'm rather boring ... I said to him once oh I'd like to go back to my counselling work oh he said go on why not? Oh I thought, I thought I just couldn't (Gina/S).

She rang me and said would you like a job as librarian here part time so I took it on and I was there 7 years. I gave it up because [the person with epilepsy] become more difficult to deal with ..... but until that point I'd been very happy (Rosemary/P).

It is equally important for the caregiver to have some relaxation. Having part-time work is an excellent way to feel part of the ordinary community as is being able to attend social functions as an ordinary person. Sometimes this is as part of the disabled community where everyone has the same experience.

It was just wonderful because we went and nobody took any notice of us and you know we were just there and one of the crowd and it was just lovely (Sandra/P).

However it is also important to take part in ordinary social activities like Adult Education classes or going to a party:

I've always had an interest in art and I started doing classes ... and I've continued art on as an interest since. It's great therapy (Rosemary/P).

I really hate going out ... and people talking about it all the time. I go out to forget about it (Terri/P).

On the other hand, when this is not possible, caregivers may become resigned to their situation, or find that the experience is sad without the person with epilepsy:

We don't go out because we can't find anyone to babysit ..... We haven't been out [without the children] probably for about 4 years...because there's no one to leave [person with epilepsy] with.....people don't tend to want to. They are a bit worried ...in case... [the person with epilepsy] takes a seizure (Mel/P).

Fear and uncertainty both provoke, and result from, situations where these caregivers are forced to consider unorthodox measures in order to access ordinary services and benefits that they consider should be available to them. Social expectations that families will support them through the illness, that the education system will make provision for them, that other people will regard them in the way they always have are shown to be incorrect. Emotions that emerge from breaches of expectations are

dependent on the intimacy of the relationship. Breaches of expectations of family support are regarded with understanding tinged with sorrow and occasionally bitterness. The more remote the social group or institution, the more likely it is that the emergent emotion is anger. This is in contrast with studies of people with chronic illness which often find instances of emotional conflict in the relationship between caregiver and the sick person (Corbin and Strauss 1988, Speedling 1982, Williams 2000).

"Temporal dynamism", the process through which group emotion acts as a catalyst for change, is also evident in breaches of expectations that re-occur. One of the many examples of this was illustrated by the pursuit of a better deal for post-school care, which shows how emergent emotions also culminate in social action; in this particular instance the formation of a political lobby group.

Over time, caregivers find that social institutions have only a few poorly-funded mechanisms to deal with chronic illness. Finally, if the *status quo* becomes unacceptable, caregivers are driven to act as advocates on behalf of people with epilepsy and attempt to alter the social structure to accommodate those less able. Caregivers feel that they have been placed in a situation where social benefits are available to others but not to them. This situation is unacceptable, particularly when they are forced to deal with issues of social stigma, exclusion and devaluation.

Marginalised people often resort to means which others may consider unorthodox in an attempt to gain social recognition (Millen and Walker 2000). These caregivers are no exception. Unorthodox behaviour is motivated in two ways. First by identification with the person who has epilepsy in a form of "courtesy stigma", the process in which stigma directed at the sick person is perceived to be also experienced by the caregiver (MacRae 1999: 57). Secondly, when a caregiver takes on the role of "protector" of the person with epilepsy (Williams 2000: 269).

Illness is generally not subject to social sanctions, but it is a condition that is excused from sanctions, as Parsons has indicated (1967), only because it is temporary. People

who are ill are expected to do everything they can to recover. If they do not, they are considered to be deviant: first, through non-conformity with the expected return to health; secondly, through being seen to be discredited by the appearance of "an undesired differentness" (Goffman 1968: 15). In the same way, caregivers become non-conformist when they realise that others view the person with epilepsy as different. They become activists and advocates. When their spouses or children are labelled, caregivers insist on social understanding, because they have a symbiotic relationship with the people they care for. When children with epilepsy are denied access to education, work, or respite care, caregivers combine to fight the system. It is a practical expression of the genesis of social change, particularly when caregivers combine to form pressure groups.

## **CONCLUSION**

Caregivers would not experience marginalisation if institutions were structured in such a way that all illnesses were given the same care and attention. As a chronic condition, epilepsy belongs to a group of illnesses and conditions for which there are presently no structures. The responses of caregivers show one way in which social systems are changed: through the frustration and anger of people who find themselves in a similar situation. These emotional responses build in a way that acute illnesses do not, because there is a long-term temporal component. Discontents, which may be ignored or accepted over a short time, become magnified when experienced over a long period.

## **CHAPTER 9 - DISCUSSION AND FUTURE DIRECTIONS**

Even when an ill person treated them with anger and disdain, denied that they were sick, completely disrupted the coherence of everyday life, and did things that were incomprehensible, distressing beyond measure, socially repugnant, or downright dangerous, love often kept caregivers caring (Karp 2001: 16).

Is the construction of epilepsy the same for caregivers as it is for the person with epilepsy? This final chapter reviews the thesis in response to this question and concludes that they are not the same because of the unique perspective and experience of the caregiver. The chapter also highlights the links which may be made between the experiences of these caregivers and previous studies of caregiving, and continues with a discussion of the important differences between this and other studies. These differences are used as the basis for suggestions for future research. Caregivers' accounts can be used to link the sociology of the body and the sociology of health and illness through the caregiver's experience of uncertainty and fear. In addition, links to the research and theories of the sociology of emotions are also indicated. Finally, the implications that this research has for social policy are outlined together with recommendations for possible action.

### **9.1 Ontological insecurity**

The predictability of the (apparently) minor routines of day-to-day life is deeply involved with a sense of psychological security. When such routines are shattered - for whatever reason - anxieties come flooding in, and even very firmly founded aspects of the personality of the individual may become stripped away and altered. (Giddens 1990: 98)

Giddens argues that it is the psychological security of the individual that is shattered. However, from the results of this study it is apparent that emotional security is shattered as well. Not only are aspects of the personality affected, but also taken-for-granted assumptions of daily living including the social rules which govern interaction. For the caregivers of the people with epilepsy whose seizures are not well controlled, seizures continue to threaten expectations of bodily control and social order. Seizure activity constantly breaches expectations of normality. In Hochschild's (1998: 6) 'collectively shared emotional dictionary' of Western society fear would be the cultural

response to threatening situations. There has been little analysis of the social sources of fear although the emotion is identified frequently in research (for example, Grbich *et al.* 2001) and is the subject of many studies about its cognitive and physical effects (for example, Cant 1994). Linked by the expectations of caring, the experience of seizures shatters the security of the caregiver.

The consistent reporting of expressed emotion in the experience of caregiving (see for example, Charmaz 1983; Corbin and Strauss 1988; Karp 2001) is echoed in this research. Expressions of uncertainty and fear underpinned the accounts of most of the caregivers, especially those who cared for people with poorly controlled seizures. This research shows that the body of the sick person is linked to the emotions of the caregiver through the experiences of seizures, and by the emotional residue that remains when the seizures have ceased. I argue that the actual and potential consequences of seizures lead to the disruption of everyday order to the extent that caregivers experience *ontological insecurity*. This in turn creates fear and uncertainty. Such understandings relate to the unique qualities of epilepsy: little known, poorly understood, stigmatised, unpredictable and idiosyncratic. Seizures that appear without warning effect bodily changes that confront social understandings and expectations of bodily behaviour.

Caregivers' lives become a series of reactions to crises, and the experience of fear and uncertainty is constantly re-visited. However, it is apparent that caregivers react very quickly to express fear at what is happening to their spouse, partner or child. Caregivers initially experience fear of bodily disorder but move to an understanding that the bodily display is an indication that the person with epilepsy is in a position of danger. Each seizure becomes its own little emergency. In the words of Rosemary/P, caregivers are constantly 'on stretch' in their attempts to anticipate danger. Seizures thus become symbols of danger.

Seizures are the principal source of fear for the caregiver because the main concern for caregivers is the safety of the person for whom they are caring. This is culturally linked to perceptions and understandings of the caregiving role. As the primary

obligation of the caregiver is to keep the cared-for alive and well, the experience of seizures is confronting. The less controlled the seizures the more risky life appears and the more risk, the more the experience of fear. Caregivers' perceptions mean that even when epilepsy is well controlled it has connotations of risk, and therefore fear is experienced.

Caregivers experience two kinds of fear. The initial fear of seizures, which might be called "*manifest fear*", appears only until the caregiver becomes accustomed to the bodily appearance of seizures. Some caregivers may always experience this fear because of the danger that seizures represent for the sick person, as for example, if the person with epilepsy goes into potentially life-threatening status epilepticus (continuous seizure activity). However seizures confront interaction norms because they occur unpredictably and are uncontrolled. If fear is an emotion that can be controlled by social means (Giddens 1991: 44), these caregivers find the reverse. Fear is controlled by removing the person with epilepsy from danger, but when the cause of danger cannot be accessed, removed, or controlled, fear persists because danger persists. "*Latent fear*" remains as a residual effect even when the apparent cause, the seizure, has been routinised.

Ontological insecurity is exacerbated by the caregiver's experience of time, which has one of the most dramatic impacts on the caregiver. As a constant and reliable social construct, time collapses. In Melucci's (1998) terms (discussed in Chapter Three) social time and inner time are conflated. This occurs because epilepsy controls the experience of time for the caregiver. Public timetables bear no relation to the schedules of caregivers who deal with epilepsy. Breakfast, bath or meal times may be interrupted, prolonged or terminated if a seizure occurs. Not only the present but the future is affected. The future is a casualty of unpredictability and lack of control. Caregivers think optimistically of the future in terms of hope, but practically in terms of uncertainty. Where formerly time was measured and reliable, time for the caregiver of a person with epilepsy becomes linked to the unpredictability or the possibility of seizures. Life is lived in the interval between seizures and fear of the next seizure informs the kinds of activities that go on during that interval. Epilepsy links

caregivers with the sick people for whom they care through their emotional reactions to seizures. The potential for harm exists because the seizure has appeared without explanation or understanding and the caregivers' emotions remained linked because of their ongoing experience.

## **9.2 Caregivers and the institution of medicine**

Since aberrations of the body have become the domain of medicine, caregivers seek a cure for epilepsy from the health system. A fresh source of uncertainty results from their interaction with health professionals and the medical institution, as the result of a discourse that is understood normatively to promise diagnosis, cure and care for bodily ailments.

Caregivers come to understand the contrary: that diagnosis is difficult and uncertain, that cure is problematic and care is provided, not by the hospital, but by the home. Through the chronicity of epilepsy they discover, over time, that the medical understanding of epilepsy is not only limited but that it is quite often based on trial and error. Even medical texts admit the difficulty of a firm initial diagnosis (Taylor 1996: 40). There is so much yet to learn about epilepsy that it takes neurological experts, together with very sophisticated equipment, to make definitive diagnoses, and even then there is room for dispute. Despite this, and the knowledge that many other conditions may cause seizures apart from epilepsy, diagnoses continue to be made by health professionals who may see only a few new cases of epilepsy each year, and who have not kept up to date with the latest drugs or treatment strategies.

The management of epilepsy may also be problematic. Caregivers are aware of the experimental nature of prescribed drug dosages. Individual reactions to drugs cannot be calculated accurately and dosages have to be "tweaked" to find the optimum amounts which should be given. There are no drugs without side-effects (Taylor 1996: 47), and so these represent another kind of medical problem which caregivers must recognise, because some of these side-effects indicate toxicity or at times, life-threatening situations. Medication then, represents another source of fear for the

caregiver. This applies whether or not the epilepsy is controlled, the medication the most appropriate and the dosage correct.

Caregivers often express frustration and anger with the health system. There is a huge difference between the experience of care in a medical situation and the care of a chronic condition at home. Unlike careworkers, caregivers are untrained and unprepared for the management of chronic conditions. Caregivers in this research, who were more aware of important aspects of the type of epilepsy, and had access to adequate information, were more confident than others. They expect to receive information about the condition and about aspects of management, and they become angry when this is not provided.

Uncertainty is also created by the application of professional boundaries. There is a substantial amount of research which comments on the way in which professionals learn (Fox 1957, 1980; Light 1976) and the way in which specialist information is one of the definitive indicators of a professional body (Friedson 1970; Willis 1983). Other researchers have commented on lay evaluations of medical practice (Williams and Calnan 1996), lay understandings of illness (Thorne 1993; Freund and McGuire 1995) and lay referral systems (Scambler 1991). However, the relationship between the way in which caregivers or patients learn and absorb medical information, and the way in which professionals do, does not appear to have been addressed.

Health professionals and caregivers learn the same way, although an asymmetrical relationship may exist in terms of observational and informed knowledge. In terms of book-learning the professional may be better informed, although this cannot be taken for granted. In terms of observation of a specific seizure type, the caregivers are likely to be better informed, since they are much more likely to observe these particular seizures. Since epilepsy is not common compared with other medical conditions like a broken arm or earache, and varies so much between and within seizure types, caregivers often know much more about a particular type of epilepsy than the health professional, particularly at the general practice level. They may also be as well, or better, informed about medications and the effects of medications.



Caregivers are often forced to acquire information from other sources: from neighbours; from the local epilepsy association; from libraries; and from the Internet. In the process of acquiring information in verbal or text form, they are also acquiring practical expertise in the behaviour of the particular epilepsy that they observe on a daily basis. They become “alternative experts” in the management of epilepsy. This expertise is rarely recognised by health professionals, and often openly discounted. It is ironic, given this background, that many health professionals discount the expertise of the caregivers. The very procedures which uphold professional status, act against the sharing of information and expertise which is in the best interest of the person with epilepsy, and which both parties want as an end result. Moreover, if doctors do not admit their lack of knowledge, the result is a loss of trust between doctor and caregiver. Surprisingly, some caregivers indicate that the loss of trust is not so important if the relationship with the primary health carers is a collegial and emotionally supportive one, despite the caregiver identifying weaknesses in knowledge, expertise or care.

Frustration with health professionals builds over time into anger that may have many causes. These include: lack of respect for the knowledge of carers; recognition that people with epilepsy are put at risk by poor management of the condition; and the knowledge that the discourse of medicine professes expertise that is often not delivered. This occurs, for example, with decisions about the most appropriate drugs for a particular epilepsy. Thorne (1993: 195ff) reported similar reactions from families of people with other chronic illnesses. Caregivers are often so frustrated and angry that they step outside the boundaries of gendered and caring roles to confront health professionals and the obstacles that are placed in their way by the structures of the medical systems. Caregivers learn to become activists and advocates.

Garfinkel's (1967) research has dramatically illustrated the kinds of social expectations people have of even the most minor of social interactions. This research shows that the same expectations apply to institutions. Emotional reactions to breaches of expectations of the health system are strong because the health system is the social face of safety for the person with epilepsy.

### 9.3 Caregivers and other institutions

Medicine is not the only institution that produces frustration and anger in caregivers. The education system also becomes a source of uncertainty and anger when educational structures come to represent a threat to the safety of children with epilepsy. For example, careworkers at a school, unconvinced by a caregiver's account of the dangerous nature of her child's epilepsy, did not change their minds until an ambulance team had to be called to provide resuscitation. Even then, they were resistant to the provision of special care, and made special arrangements only when the caregiver went to the top administration of the Education Department in an attempt to have the decision reversed. Other caregivers report similar difficulties in their attempts to have structures created for post school care.

These experiences not only reinforce feelings of fear and uncertainty in caregivers, but also frustration with the caring contract, which they understand involves mutual obligation. Women, in particular, are expected to perform caregiving duties (Baldwin and Glendinning 1983; Glazer 1988). To match the expectations of caregivers that they have a duty and obligation to care, they have in turn, expectations that other people will understand the condition or illness and the situation of the caregiver, and expectations that caregivers and their families will be included in society, not excluded. They often find that this social contract is one-sided. Like Vietnam veterans, the sacrifice of caregivers is rarely rewarded.

The expectations which caregivers have of institutions also apply to expectations of other parts of society. Uncertainty, fear, frustration, anger and sadness are experienced when caregivers approach family members, friends or others for help. Epilepsy becomes understood as an unexpected barrier not only to hitherto expected assistance, but also to relationships. Family members who cannot cope with the chaotic body of the person with epilepsy keep away, or show their fear. Caregivers expect the support of family and friends; however, social support for illness is geared towards acute illness with a limit on the sympathy margins that can be invoked (see Clark 1987).

In circumstances where people will rally to help those with acute illness, commitment over time is restricted to those who are close to the caregiver, *and willing* to take on part of the care. That this is unusual is reflected in surveys such as that done by McLaughlin (2001) who reports that respite care is a priority for caregivers, indicating a lack of community support. Sadness, and sometimes bitterness, is expressed when family members do not help, or provide respite for the caregivers, although caregivers understand why others may not feel comfortable doing this. Caregivers report that people in the community show their intolerance of difference unless there is a background of understanding. Caregivers begin to judge the extent of public ignorance of epilepsy and to identify instances of stigma. Some caregivers accept this as a result of a 'don't complain, don't explain' Australian ethic. Others, particularly the younger caregivers, resist ignorance with a demand for better public education.

The emotions experienced by caregivers of people with epilepsy are directly related to the social understandings that are absorbed through the medium of Australian culture. The caregiver's understandings of bodily behaviour, the expectations of medical professionals and institutions produced through medical discourse, the mutual obligation of the caring contract and patterned interactions with family, friends and neighbours are all affected by the experience of epilepsy. Uncertainty and fear are the result of unexpected changes in social circumstances and frustration and anger are often the result of continued uncertainty or continued fear. When people combine to deal with the situations that have caused such strong emotions about existing social structures, temporal dynamism may lead to social action.

#### **9.4 Concepts from other research**

Previous research shows that people with epilepsy report experiences of stigma, loss of self and social isolation. Their perceptions of caregivers include issues of overprotection and concealment. Similar issues are addressed by caregivers in this research but their unique perspective shows that their experience of epilepsy, even when a similar issue is canvassed, is different from that of the person with epilepsy. Most caregivers, for example, although perceiving instances of stigma, do not react by expressing shame, or any of the other reactions predicted by Goffman (1968). Nor do

they act as stigma coaches (Scambler 1989). Instead they react with surprise, or anger, at the lack of social understanding displayed on such occasions. This is a distinct change, supported by the majority of the caregivers in this study and also noted by Millen and Walker (2000) in respect of their research with people with disabilities.

Social isolation (see Klein *et al.* 1967; Foxall *et al.* 1986) is actively resisted by caregivers in this research, whether by expressed intention, or by actively taking part in activities which are theoretically open to all. Younger caregivers in particular regard involvement in any social activity as a right and not a privilege. However, there is some ambivalence. Some caregivers express their right to attend any social occasion or event, at the same time saying that it is easier to eat at home, or to be present at events where everyone understands any difficulties you may be experiencing.

A tendency towards overprotection is acknowledged as a problem by young and older caregivers alike. Since the safety of the person with epilepsy is manifestly the principal concern for caregivers, being alert to situations that appear to be dangerous is a normal part of the caring role. Caregivers are aware that people with epilepsy resist this surveillance and try to be covert in their supervision. However, the desire for independence on the part of the person with epilepsy has to be balanced with the need for the caregiver to keep them safe. Modifications are often made to houses, furniture and communication systems in order to provide some element of independence. In some extreme cases, caregivers have moved house in order to provide a safer physical environment for the person with epilepsy. There is often a very fine line between the duty of care and the traps of overprotection.

Caregivers of people with epilepsy have many similarities with caregivers of people with other chronic illnesses. As well as physical exhaustion, the emotional stress from continuing fear, uncertainty, frustration and anger makes respite a high priority for caregivers (ABS 2000; Ashworth and Baker 2000; McLaughlin 2001). Most of the caregivers in this research provide care for 24 hours each day, receive no weekend breaks, no public holidays, no annual leave away from work, no special training in an

increasingly medicalised field and no de-briefing after trauma. It is amazing that so many of them are able to continue caring. Careworkers, by comparison, would receive much better pay, overtime, superannuation and workers compensation insurance. Caregivers are aware of their contribution to the economy, and some are bitter about the difference between the cost of institutional care and the amount that governments allocate to home care.

Studies of uncertainty and fear show that the expression of such emotions cannot continue without damage to the person experiencing them (Turner 2000), so caregivers attempt to impose predictability through routine procedures which assist them to regain some semblance of normality in their lives. Routinisation exists as a kind of 'magic' ritual (Malinowski 1954) which enables them to create a "normal" frame for behaviour and in which the unpredictable can be accommodated without too much disruption. Since seizures are unpredictable they cannot be included in daily planning but caregivers can try to control all other aspects of life so that seizures make the least amount of difference. Imposed predictability applies to such things as meals prepared in advance, medication dosages prepared, alternative arrangements for transport and stand-by arrangements for other family members.

The processes of "normalisation" which Davis (1963) describes (cited in Knafl and Deatrick 1986: 216), are used by family members to minimise the difficulties of the person with a chronic condition. Some caregivers in this study use the same management strategies in their efforts to control the uncertainty of epilepsy. The difficulties of daily life are minimised by the expressed view that one life is just like that of any other person. Andrew/S says:

...it's just been fantastic the way we've just led a reasonably normal ... family life with our ups and downs of course, with kids and so forth, but I think it's made us fairly tough and we always say that there's someone worse off than ourselves when we see people in wheelchairs or one leg...or whatever.

The use of "normality" by these caregivers was a flexible instrument. On the one hand they describe their apparent normality, and on the other they relate instances that were plainly not normal. However, they also acknowledge the hidden aspects of

epilepsy that prevent others from knowing how far from normal life a caregiver can actually be. For the most part being normal refers to situations when their activities coincided with what they considered people who were not caregivers might be doing. But normality is also expressed in terms of a desire to be with people who understand the situation, or the pleasure of having a few hours of work outside the home, or in the joy of significant achievements made by the person with epilepsy and sharing happy times with them.

The importance of access to part-time work, as both an economic and recreational necessity is evident in this research. Previous researchers report that there are some gendered differences in the approach to work, with women, for example, showing more appreciation of part-time work than men (Fengler and Goodrich 1979; Baldwin and Glendinning 1983; Fitting *et al.* 1986). With only two males in the sample, it was difficult to make a comparison. However, both had interests outside the home; one was involved in part-time work and the other with volunteering activities. The women who had experienced part-time work, or were presently involved in work, were extremely appreciative of the opportunity.

Other studies note the importance of receiving information about illness, about the future course of the illness, and service provision (for example, Schneider and Conrad 1983). In McLaughlin's (2001: 18) study, the provision of information about services and information about the child's condition is ranked highly by both rural and urban caregivers. Amongst patients attending a Belfast clinic 90% wanted more information about the disease', and 75% wanted more information about drugs (Taylor 1996: 8). A simple thing, such as naming the condition as epilepsy (or a type of epilepsy) is valued. This empowers the caregiver to be able to discuss it as a common social "thing" with professionals and non-professionals alike.

A specific name is also important because the usual epilepsy texts for non-professional caregivers and sick people describe seizures in broad types and may not be helpful to those who need to know about more rare types (Murray 1993: 175).

Schneider and Conrad (1983: 166) report that their respondents 'spoke often about how limited and vague the information was that their doctors provided'.

In summary, the most significant difference in the experience of caregivers of people with epilepsy from the experience of people with epilepsy and other caregivers is ontological insecurity. It is not surprising that people with epilepsy did not experience this, as in the majority of forms of epilepsy, people who have the condition are not conscious of their appearance. Other research into caregiving has not identified similar effects and it may indicate that epilepsy is alone in dramatically changing the life experience of the caregiver. In comparison with other aspects of the experience of epilepsy such as stigma or experience with health professionals this research shows that the caregiver has a different understanding. It is difficult to assess whether the emotional experience of caregivers is similar to that of their partners or children, as previous studies of people with epilepsy did not include this as a area of inquiry. Overall, as a group, caregivers show their experiences have more in common with each other than they have with chronically ill people.

#### **9.5 Implications for the sociology of the body, the sociology of health and illness and the sociology of emotions**

The sociology of the body provided a means by which the bodies of people with chronic illnesses could be linked with social processes. This research indicates that the bodies of caregivers are also affected by what is happening to the sick person through the medium of emotion. In other words, it is not only the bodies of sick individuals that can be studied, but also the bodies of those who have emotional relationships with them.

This research has shown that the caregivers' construction of epilepsy is an extremely traumatic emotional experience. During the analysis of the interviews it was noticeable that caregivers regularly linked their emotional experience with a social cause, specifically with the breach of normative expectations. Typical expectations of the cared for person which were breached were connected with the proper control of the body, predictability of daily life and actions, caregiving (particularly preventing

danger) and the expectation of social order. This research is significant because it links the actions of caregivers to what is happening to another's body.

This broadens the concept of chronic illness to include caregivers in a previously untheorised way. Caregivers are bound to family members by the expectations of the health system and also through cultural understandings and the socialisation processes of families. This research shows that caregivers experience emotions as a result of the illness experienced by another. Emotions appear as filters that assess the normative dimensions of acts. This emotional filter process allows actions which are as expected to continue without any reaction from the individual. Actions however, which do not meet or exceed expectations (that is, breach expectations) cause an emotional response. Fear and uncertainty were regular reactions to breaches of these norms. Further analysis suggested that there were other dimensions of the experience of the caregiver with regard to emotion. Expressed emotions were intimately *linked to social expectations in a causal nexus*. Caregivers themselves identified the source of their emotions. Elizabeth/P gives one example

...he gave me no information whatsoever. I actually had to - I rang the Epilepsy Association and got all my information from them...*I felt really angry afterwards because I felt that he should have given me the information...* (my emphasis in italics)

Studies of chronic illness have previously described the existence of different emotions without linking emotion to expectations. It is apparent when reading the accounts of participants in studies such as those of Karp (1996) and Corbin and Strauss (1988) that emotion is closely connected with normative expectations of other individuals and of institutions. A short extract from Charmaz (1983) illustrates the juxtaposition of emotion and social cause:

The thing that did it was that she wanted to come in and take care of me as a nurse. I couldn't accept that. I cried....When a nurse comes through your door as a nurse, that's one thing...but to have your mother-in-law cleaning up after you and bathing you, that's another - it is just too much to take (1983: 186).

This study supports the theory of emotion proposed by Turner (2000) with respect to the connection of expectation and emotion. Turner's hypothesis suggests a more



complete theory of emotion for the findings of this research, one which is not time dependent, nor limited by constraints of power dimensions or other structural elements. Because it is based on the moment of interaction and the expectations which interaction contains, it offers a much more readily accessible explanatory framework than other theories of emotion for the range of emotions which caregivers experience. Caregivers' emotions emerge at times in which social expectations of a particular situation are breached and this is often expressed very clearly as shown by Elizabeth/P above. The limitations of this study prevents any comment on other aspects of his theory such as the origin of social bonds or whether there is a hierarchical order of emotion. However it is plain that emotions are strongly connected to the maintenance of the process of social interaction.

There is also support in this study for the management of emotions proposed by Hochschild (1983) not only of self but of others, and the limits of sympathy and obligation suggested by Clark (1987). The concept of emotional anomie (Karp 2001) describes turbulent emotions, but does not address the source of these emotions, the breaching of expectations. It was not possible to properly address Karp's (2001) proposed emotional career of caregiving as this was not a longitudinal study. These caregivers were at different stages in their experience of caregiving and seemed to express some similar emotions at all stages. Individual caregivers, on the contrary, often routinise emotions, such as fear of seizures, and the concepts of manifest and latent emotions may be more useful to explain why some strong emotions appear to emerge suddenly. This is because latent emotion persists until the source of the original emotion is removed.

The feelings of fear and uncertainty continually cause ontological insecurity, not only through the experience of seizures, but also through the effect of epilepsy on other social structures. This process echoes Karp's discussion of the progressive building of emotion (2001) but because of the contradictory results of this research may need more investigation. Sometimes, for example, fear is routinised (as in the experience of most seizures). However, sometimes fear is not, particularly when it applies to an always life-threatening situation. Caregivers in this study do not support temporal

dynamism unless in concert with other caregivers. Emotions such as anger emerge if expectations are not met, but are exacerbated if an emotion is experienced simultaneously by other members of a group. Emotions may therefore provide the impetus for social action and perhaps for social change. These are all areas that may prove to be fertile fields for future research.

## **9.6 Applications - pragmatic and ideal**

The caregivers in this study expressed fear and uncertainty in response to many socially structured situations that could be changed. Health professionals, for example, could recognise the caregiver and/or people with epilepsy as equals in the *caring network*. In this way, health professionals would show that they respect the caregivers' knowledge and experience of epilepsy as different, but valid. In addition, much of the fear associated with diagnosis could be ameliorated by establishing a *procedure* for the treatment of epilepsy in line with suggested best practice in the UK that is, diagnosis and treatment should be made as accurately and as quickly as possible, relayed to the person with epilepsy and the caregiver, referral should be made to a general practitioner for primary health care and then to a community epilepsy association for up to date information, counselling and assistance (Taylor 1996). Finally, an *illness management plan* for the future care of the person with epilepsy, outlining options if the epilepsy cannot be controlled, may provide more security than simply reacting to crises as they arise. Such a three-part programme could considerably reduce the initial fear and anxiety and reduce situations that may provoke anger. This is important, particularly since this study shows that people remember negative experiences associated with illness and treatment, and develop emotional resistance to careworkers if their experiences are reinforced.

The importance of providing current information to people who care for someone with a chronic illness has been addressed by many studies (for example Murray 1993; McLaughlin 2001). Medical practices could take into account the expectations of cure and care that caregivers have and fully inform caregivers of issues relevant to the kind of epilepsy for which they will be caring. If this means that health professionals have to liaise with epilepsy-specific organisations that are able to provide ongoing

information and support, this can be included in an illness management plan. One of the simplest measures for alleviating fear would be provision to train caregivers to nurse and care for chronically ill people through, for example, first aid courses, Adult Education or TAFE short courses. These courses could also be run by community-based epilepsy support organisations.

## **9.7 Public policy**

The other structural change relates to social perceptions of epilepsy. Caregivers repeatedly report that much of the exclusion they experience is due to aspects of stigma, ignorance of epilepsy as a condition, and knowledge of the way it affects families. Publicity campaigns such as those addressing HIV/AIDS and smoking have been visibly successful in changing public attitudes to social issues. However, this requires a substantial allocation of public funds which are already in short supply.

The most effective change would be the re-allocation of health funds from the hospital and acute-care sector to public health. Most chronic illnesses, such as epilepsy, would benefit from such a shift. There is a necessity to support caregivers by providing respite care, more resources and adequate income so that they can continue to provide an alternative care system. The finding that the contribution of caregivers (providing 20 hours a week unpaid care for people with chronic illness in the UK) was more than the total paid workforce of the national health system (James 1998: 218) indicates the magnitude of their contribution to the economy.

The impact of emotions on caregivers is emerging in the social costs of continuing care and can only get worse if policies that advocate the medicalisation of the home are combined with an ageing population. While most people acknowledge that good home care is better from the viewpoint of families and sick people, governments must also acknowledge that this cannot be done without more support.

Since social expectations are important for social stability and order, institutions must establish what expectations are, before social action takes place. Whether this is a plan to change social attitudes, to provide caregivers with the support they need or

whether it is a matter of changing structures to make the physical environment more inclusive, expectations will influence the outcome. Otherwise expectations may be developed in the general population that cannot be met and therefore will lead, inevitably, to disappointment and possibly anger.

## **CONCLUSION**

The experience of these caregivers provides a rare opportunity to observe the process by which emotions connect the individual and social structure. I have argued that the construction of epilepsy for the caregiver is characterised by a situation of uncertainty arising from characteristics of the condition: inaccessible, unpredictable, incurable, idiosyncratic. Ontological insecurity is the basis of continuing fear and uncertainty experienced by the caregiver. Caregivers attempt to re-establish control of uncertainty, but where this fails, fear persists.

The experience of epilepsy not only affects daily patterned interaction at the micro level but also strains and threatens the stability of larger institutions. Seizures change the behaviour of the person with epilepsy and also that of the caregiver and family members who are bound to the person with epilepsy through patterned social obligations. Social norms exist which provide a regular predictable framework for social interaction. When seizures occur the social framework is dislocated and sometimes broken irretrievably. This research describes the way that caregivers experience epilepsy and how this affects their lives, showing how emotions are created in social interaction and how this leads to social action. Much of the anger experienced by caregivers emerges from expectations that are not fulfilled. From a sociological perspective this kind of anger may be ameliorated or even abolished by social structural changes.

## **APPENDIX A - Caregiver details**

In the interests of anonymity real names have not been used in this research and where other aspects of the lives of participants might identify them, these references have been removed or altered. The identifier 'P' (parent) or 'S' (spouse) identifies this aspect of the relationship with the person who has epilepsy. All the interviews were tape recorded in the caregiver's home and transcribed later by the researcher.

### **Gina**

Gina is retired and cares for her husband to whom she has been married for over 30 years. They have a grown up family, with some members living interstate. Gina and her husband are respected members of the community and have been active in many different organisations. This interview lasted over two hours and was interrupted once for about twenty minutes when a visitor arrived. The person with epilepsy has another medical condition for which he receives health centre support.

### **Rosemary**

Rosemary is retired and has been living with her husband in the same community since she was married. She has tertiary qualifications and gave up work nearly 30 years ago in order to care for her child, the person with epilepsy. This was the first interview and Rosemary had prepared notes to help me understand the kind of epilepsy she was caring for, and its effects and management. The person with epilepsy receives a pension, is eligible for respite care and there are other health needs.

### **Sandra**

Sandra is a young mother who has three small children. One of her children has epilepsy and attends school. She lives near her extended family and benefits from their support and help. The community has no health centre, or easily accessible medical support. The interview took an hour and twenty minutes.

Terri

Terri has two small children and lives in a small community with her husband. She has a part time job and cares for one of her children, the person with epilepsy, with the help of family, friends and careworkers. Terri has close and frequent contact with doctors, specialists and a condition specific support worker. The person with epilepsy is eligible for respite care, and has other physical needs that must be met. The interview lasted for an hour and a half and was interrupted by a visitor for a few minutes.

William

William lives in a large community with his second wife, who has epilepsy. His first wife also had a chronic illness. William and his wife are active in the community with voluntary organisations and have a large circle of friends. William's wife is independent but has another problem that sometimes restricts mobility. The interview had been going for thirty-five minutes when the person with epilepsy arrived home. We concluded the interview with a further ten minutes after lunch.

Andrew

Andrew and his wife, who has epilepsy, have been living in the same community for many years. They have a grown up family, although members of Andrew's extended family do not live close. They both have very strong religious beliefs. Andrew has a part time job. This interview took place with the person with epilepsy in the room. It lasted for an hour and ten minutes.

Elizabeth

Elizabeth is married with two children, one of whom has epilepsy, and lives in the same community as her parents. She has tertiary qualifications and works part-time while her children are at school. This interview lasted for forty minutes.

Mel

Mel lives in a large community with her husband and children, one of whom has epilepsy. She does volunteer work with a number of organisations while her children are at school. The person with epilepsy also has developmental delay but not sufficiently severe to attract a special aide. The interview lasted for an hour.

## **APPENDIX B - Topics for discussion**

- life before epilepsy
- work, social life, family
- management of the illness, issues of control
- seizures
- home environment
- taking medication, diagnosis, doctors
- importance of spiritual beliefs
- identification with particular ethnic groups



## APPENDIX C

### INFORMATION SHEET

#### Carers

#### *"The Carer's Construction (Understanding) of Epilepsy"* Research Project for a Masters Degree in Sociology

*Thank you for volunteering to help me with my research. During the research I will be talking to carers of people with epilepsy in order to build a comprehensive picture of the way that epilepsy has an effect on the life of the carer. Our conversation will take about an hour. It will take place wherever you are most comfortable - either at your home or a mutually agreed location. I will ask you to talk to me about your experiences as a carer of a person with epilepsy.*

*I am undertaking this research, under the supervision of Associate Professor Gary Easthope, as part of my Master of Arts degree in Sociology. I became interested in epilepsy because my partner had epilepsy and I was his carer. I am, at present, the President of the Epilepsy Association.*

*The research has received ethical approval from the University Human Research Ethics Committee. As part of the ethical provisions you will be asked to sign a statement of consent. A copy of the information sheet and the statement of consent will be given to you to keep. If you wish to stop at any point because you become upset I will understand. You may wish to continue at a later time or you may wish to withdraw from the research. If, as a result of talking to me, you feel that you need someone with whom to discuss your experiences more fully, I can refer you to appropriate counsellors of the Epilepsy Association of Tasmania or Headway.*

*After the interview the conversation will be typed by me and the tape and the typewritten copy stored under lock and key. When the research is completed and written up, the tapes and conversations will be similarly stored until the material is no longer required. It will then be shredded and the tapes 'wiped' electronically. Your contribution to the research will be confidential and will be kept anonymous in the research reporting.*

*If you have any concerns or complaints at any stage during the research, you may contact my supervisor, Associate Professor Gary Easthope (Phone: 62262355, Fax: 62262279, email: [Gary.Easthope@utas.edu.au](mailto:Gary.Easthope@utas.edu.au)). Alternately you may contact the Executive Officer of the University Human Research Ethics Committee, Ms Chris Hooper - phone 03 62 262763.*

*A copy of the masters thesis, when complete, will be available for you to read at the office of the Secretary, School of Sociology and Social Work, University of Tasmania.*

*Helen Hutchinson.*

## STATEMENT OF INFORMED CONSENT FOR CARERS

### Research Project for a Masters Degree in Sociology *"The Carer's Construction (Understanding) of Epilepsy"*

1. I have read and understood the 'Information Sheet' for this study.
2. I understand that I will take part in an interview of approximately an hour concerning my personal experience of epilepsy and the interview will take place at a mutually agreed location.
3. I understand that if I become upset I can stop and request help from counsellors.
4. I understand that all research data will be treated as confidential.
5. Any questions that I have asked have been answered to my satisfaction.
6. I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.
7. I agree to participate in this investigation and understand that I may withdraw at any time without prejudice.

Name of subject .....

Signature of subject ..... Date .....

- 
8. I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of investigator .....

Signature of investigator ..... Date .....

## **APPENDIX D**

### **COVERING LETTER FOR SURVEY**

Date

Dear Member

I am undertaking research, under the supervision of Associate Professor Gary Easthope, as part of my Master of Arts degree in Sociology. As part of my research project I need to collect some general statistics on carers of people with epilepsy. The attached questionnaire is designed to provide general information about carers that I can use in an anonymous way in the research.

It will also assist the Epilepsy Association. Every year we must inform the Department of Health and Human Services of the kind of services we offer to people with epilepsy and their families so that they can determine funding for the following budget period. It would be helpful if we had some statistics on which to base the need for future services and also some indication of the characteristics of our client base.

I would like to contact as many people as possible who care for someone with epilepsy. If you are a carer I would appreciate it if you would fill in the questionnaire and return it to me using the reply paid envelope, or fax it to E.A.T. on 6234 6967.

If you wish to assist me with the research project interviews, please fill in the section at the bottom of the survey form as well.

Please do not return the questionnaire if you do not wish to do so. If you have any concerns or complaints at any stage during the research, you may contact my supervisor, Associate Professor Gary Easthope (Phone: 62262355, Fax: 62262279, email: [Gary.Easthope@utas.edu.au](mailto:Gary.Easthope@utas.edu.au)). Alternately you may contact the Executive Officer of the University Human Research Ethics Committee, Ms Chris Hooper - phone 03 62 262763.

Yours sincerely

HELEN HUTCHINSON  
President, Epilepsy Association of Tasmania.

# **EPILEPSY ASSOCIATION OF TASMANIA SURVEY**

AGE: (please tick)

- 18-30 ☐
- 31-45 ☐
- 46-60 ☐
- more than 60 ☐

GENDER:

(Please circle)

Male

Female

RELIGION: (please tick)

- Anglican ☐
- Roman Catholic ☐
- Other (please specify) ☐
- .....

EMPLOYMENT STATUS: (please tick)

- Full time ☐
- Part time ☐
- Casual ☐
- Home management ☐

ASSOCIATION WITH PERSON WITH EPILEPSY: (please tick)

- Parent ☐
- Spouse or partner ☐
- Sister or brother ☐
- Other relative ☐
- Friend ☐
- Other (please specify) ☐
- .....

NUMBER OF YEARS ASSOCIATED WITH EPILEPSY

PERSON WITH EPILEPSY (please tick)

- Less than 5 ☐
- 6-10 ☐
- 11-20 ☐
- more than 20 ☐

AGE OF PERSON WITH

(please tick)

- Less than 18 ☐
- 19-30 ☐
- 31-45 ☐
- 46-60 ☐
- more than 60 ☐

As part of my studies towards the completion of a masters degree I wish to talk to carers and/or partners of people with epilepsy. If you would like to assist with this research project, please tick the box below.

Yes, I wish to help

☐

My contact telephone number is: .....

NAME:.....

Thank you for your assistance.

Helen Hutchinson.

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